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FATHER-INFANT RELATIONSHIP DEVELOPMENT WITH AN INFANT WHO HAS SPINA BIFIDA

by

Linda Hopper Cook ©

A thesis submitted to the Faculty of Graduate Studies and Research
in partial fulfilment of the requirements for the degree of Master of Nursing

Faculty of Nursing

Edmonton, Alberta
Fall 1995

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Arnette Anderson
Dr. Anderson

Brenda C. Munro
Dr. B. Munro

Sept 27, 1995
DATE

Dedicated to my late father
James Ray Hopper
whose love and teaching
I will always treasure

and

to my husband, Bill, and
children, Heather and Scott,
who have made parenthood
a wonderful adventure!

ABSTRACT

This grounded theory study presents a theoretical analysis of six fathers' experiences of developing a relationship with their infants who have spina bifida. Through two tape-recorded, semi-structured interviews, fathers described experiences and perceptions concerning relationship development, which were analyzed using the constant comparative method. The basic social psychological process which emerged from the data was "being there for my child--no matter what." These fathers wanted a father-infant relationship which was deep, lifelong, unconditional, and mutual. The four sub-processes which helped these fathers to fully and effectively be there for their babies were: a) committing himself to being the father of this child, b) getting to know and be known, c) looking beyond the situation, and d) finding meaning in the relationship. Developing a helpful role and building and maintaining hope were strategies used to combat helplessness and hopelessness throughout the process of "being there."

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CHAPTER I -- INTRODUCTION

Over the past few decades radical changes have occurred in family life. More women are working outside of the home. Roles are determined less by gender than by ability and availability. Feminist ideas have influenced men as well as women. Men have been encouraged to adopt a more nurturing role with their infants, to be more open emotionally, and to strive for an expression of fatherhood which fits personality rather than tradition (Cohen, 1993). It is remarkable, therefore, to note that so little is known about how fathers develop their relationships with their infants.

Medical advances are improving the survival rates and future prognoses of infants with spina bifida. Families now are caring for children in the home which in the recent past would have been institutionalized. In order to promote the health of these families, and, more specifically, to assist and encourage the development of strong and healthy family relationships, it is necessary to know more about the development of the father-infant relationship when the baby has spina bifida.

The goals of this study are to identify the basic social and psychological processes involved in developing the father-infant relationship and to develop beginning nursing theory related to the process which may assist nurses in promoting the health of families who have a child with spina bifida.

Rationale for the Study

Nurses have the necessary knowledge to meet many needs in the lives of families of infants born with spina bifida. Information about grief, teaching/learning theory, and advocacy principles are all commonly found in current nursing textbooks. Research based information about family functioning, coping strategies, and social support (from the mothers' viewpoints) are used to assess family strengths and to support coping for families of infants who have handicaps (e.g. Feetham, 1980; Farran & Sparling, 1988; McAndrew, 1976). Nursing knowledge, however, is very inadequate concerning the fathers of infants who have disabilities. Often, what is mistaken for knowledge of fathers' attitudes and perceptions is really a generalization of information from mothers (Davis & May, 1991).

A "two-tiered" system of health promotion for men and women has inadvertently occurred. Mothers are visited routinely by nurses, emotionally supported, allowed to express grief, taught, encouraged, and praised for their parenting efforts. Fathers of infants who have handicaps are routinely overlooked, given information second hand from the mother, and told to be strong to support the mother (Davis & May, 1991). If fathers openly express grief or anger, then they may run the risk of being judged as psychologically unstable and potentially abusive (Davis & May, 1991). Even when a father is present for a child's clinic visits, I have observed that health care workers, both male and female, often address their comments to the mother rather than to the father.

Nurses and other health care professionals may unknowingly be contributing to the stress that fathers experience rather than promoting the health of fathers and their children by supporting the development of strong family relationships. Cherry (1989) asserts that there is great potential for health care workers to either decrease or increase stress for parents of children with disabilities by their words and actions. Burkett (1989) suggests that nurses may foster a healthy adjustment to the child's disability in these families by being consultants and care partners with the parents rather than directors of care. How can we be effective in such roles with fathers when we know so little about the development of the father-infant relationship with a child who has disabilities such as those associated with spina bifida?

Little is known about the development of the father-infant relationship with normal babies and even less with babies who have handicaps. Much research has concentrated on the mother-infant relationship, some on sibling relationships, but very little on the father-infant relationship. Twenty years ago Lamb (1975) called fathers the "forgotten contributors to child development." To a great extent, this is still the case concerning fathers of children who have handicaps. Perhaps researchers have focused on mothers because, as home makers, they might be more easily accessed. A bias toward considering mothers as essential to infant development, and fathers as optional, has been evident for many years--at least from Freud (1949) onward. Hamner and Turner (1990) quote Margaret Mead that "Fathers are a biological necessity, but a social accident" (p. 12).

Fathers were essentially overlooked in research until the early 1970's by all but a few researchers. Studies in the 1970's correlating absence or presence of fathers with child outcomes, or documenting fathers' participation in child care did not explore father-infant relationship development. Moreover, these studies did not explore the attitudes and perceptions of fathers which may have prompted their presence or motivated an active role in their children's lives during infancy. Much of the research about fathers and their children has been limited to unusual situations, pathological relationships, and father absence (Biller, 1974). Recent studies have focused on particular groups, such as gay fathers, divorced non-custodial fathers, stepfathers, disabled fathers, and abusive fathers while neglecting more foundational research on how fathers perceive and work on the development of the relationship with their infants. Even with the marked increase in research interest in fathers in recent years, the indices of most current child development and family studies books show very few entries concerning fathers in comparison to the attention devoted to mothers. Much of the meagre knowledge about father-infant relationships has been gleaned in bits and pieces from studies about families or father's roles.

The effects of the child's spina bifida on father-infant relationship development are unknown. Infants born with spina bifida often have multiple handicaps which can affect their survival, functioning, responsiveness, and future. Relating to even a strong and healthy infant can be a frightening prospect for a beginning father, but relating to an infant with a variety of problems, hospitalizations, and treatments can be a very fearful proposition. How these fathers manage to deal with the stressors of the transition to fatherhood, the complications of the baby's condition, and the development of a relationship with the baby remains enigmatic.

Research Questions

The following questions were formulated to guide the research project.

1) How does the father-infant relationship develop between a father and his infant with spina bifida?

2) What factors help or hinder the development of the father-infant relationship with an infant who has spina bifida?

Purpose of the Study

The purpose of the study was to describe and present a theoretical analysis of fathers' experiences in developing a relationship with their young infants who have spina bifida.

The information gained through this study may potentially provide foundational knowledge for future development of teaching materials designed specifically for fathers of infants with spina bifida (and possibly other handicapping conditions), programs to support and assist fathers in developing healthy relationships with their infants, and further theoretical advancement concerning relationship development of fathers and their infants who have handicapping conditions.

CHAPTER II -- LITERATURE REVIEW

The purpose of this review was to explore and evaluate recently published material related to the area of study, and to provide rationale for this research based on identified gaps in knowledge. In this chapter, I will review the literature about father-infant relationships in general and, then, more specifically relationships involving children who have handicaps. Some studies of father-child relationships are necessary to the review because many outcomes of the father-infant relationship are not evident until the child is beyond the infancy stage. Finally, I will present a brief introduction to spina bifida to provide a context for understanding how this condition may influence the development of the father-infant relationship.

Early Father-Infant Relationship Development

Studies in the literature which provide some knowledge about father-infant relationship development are of two basic types: bonding and attachment studies and relationship studies from an ecological perspective.

Bonding and Attachment Studies

Most of the current knowledge of development of the father-infant relationship is based on bonding and/or attachment studies. Much of the early interest in bonding sprang from naturalistic studies of behaviors among animals indicating a sensitive period immediately after the birth during which a mother-infant (and perhaps father-infant) biologically-mediated bond could either be enhanced or inhibited by environmental conditions (Klaus & Kennell, 1982; Rosenblith, 1992). Although the foundational study for the testing of this hypothesis with human beings was methodologically flawed by a mistake in data classification (Klaus & Kennell, 1976), a revolution occurred in obstetrical practice all over the world to allow parents more time alone with their newborns soon after birth.

Bonding studies mainly focused on the early interaction of the mother and infant, but McDonald (1978) and Sasmor (1979) assert that a similar bonding process occurs for fathers. Greenberg and Morris (1974) described engrossment as an intense interest on the part of new fathers to see, touch, and study their infants, resulting in elation, increased self-esteem, awe at the baby's perfection and bonding of the father and infant.

Inconsistency of terminology in the literature makes comparisons between bonding and attachment studies difficult. Though there might appear to be distinct differences between the concepts "attachment" and "bonding", they are often not clearly defined and are sometimes used interchangeably. Generally, "bonding" refers to initial encounters of parents and newborns and "attachment" refers to continuing contact and the relational behaviors. However, many authors consider that the process of bonding commences shortly after birth and results in attachment later on (Klaus and Kennell, 1983). Morrison (1990) defines bonding as the process of developing emotional attachment and attachment as the "emotional tie" which connects the baby and caregivers.

Most researchers have suggested that attachment is much more complex than the events during the first few moments of the infant's life, and that attachment can have profound effects on the personality development of the infant (e.g., Bowlby, 1988; Hinde & Stevenson-Hinde, 1991). Stressful family situations were identified by Jarvis and Creasey (1991) as factors which may lead to attachment problems unless effective coping with the stressor occurs. Attitudes and actions of other family members have also been identified as influencing attachment. In a meta-analysis of attachment studies, Fox, Kimmerly, and Schafer (1991) concluded that the quality of mother-infant attachment was highly related to the quality of father-infant attachment. Fonagy, Steele, Steele, Moran and Higgitt (1991) found that those parents who had strong attachments with their own parents generally developed strong attachments with their infants. Early resumption of employment by mothers has been identified as a negative influence on development of secure father-son attachment, but not father-daughter attachment (Chase-Lansdale & Owen, 1987), which raises the question whether the gender of the child may influence how the father relates to his infants in certain circumstances.

Several authors have suggested that early impressions about the infant may be very important to the development of attachment. Condon and Dunn (1988) found that a small but significant number of parents did not develop an emotional attachment to the fetus before birth. They suggested that the impressions of the infant at birth and shortly thereafter may profoundly influence the attachment process for these parents--perhaps even stimulating a self-perpetuating negative cycle of interaction for the fathers due to unmet expectations of how the baby would look and act (Condon & Dunn, 1988). Levy-Shiff, Sharir, and Mogilner (1989) supported this finding with evidence that parents' level of disappointment about their premature infant correlated inversely with the amount of interaction with the infant. Anderson (1994) identified the father's perception of the baby's attractiveness and perfection as one of the influencing factors in the initial development of the father-infant relationship. Brazelton and Cramer (1991) suggest that parents who see their baby as attractive and perfect are more able to endure lack of present reward in infant care by dwelling on the future potential of the child.

Summary and Critique

Naturalistic bonding theory does not answer the proposed research questions and raises others. If skin-to-skin contact between a parent and infant is necessary during the critical period, then what effect may early and prolonged separation for medical treatment have on relationship development? There has been considerable debate as to whether bonding, as theoretically proposed, actually exists. Although assumption of a biologically activated process of father-infant bonding is widespread (especially in popular magazines), there is little empirical evidence to support such a proposition (Palkovitz, 1988).

Attachment theory also sparks many questions. Although marked differences in father-infant relationships and mother-infant relationships in such areas as type of play preferences and teaching styles have been documented, researchers have often assumed a similar attachment process (Ricks, 1985). Cox, Owen, Henderson, and Margand (1992) and Bridges and Connell (1991) question whether the bases for infant attachment may actually be different for fathers than for mothers because they relate so differently to their infants. We do not know enough about the establishment of father-infant relationships to accept the assumption of similarity of the attachment process without question.

Whether attachment is actually a stable state is uncertain. Thompson, Lamb, and Estes (1982) found that measures of security of attachment of mothers and infants could vary over time. Cox, Owen, Henderson, and Margand (1992) found certain behaviors and attitudes of fathers toward their infants, as early as three months after birth, to be predictive of attachment security at one year.

Much debate has occurred concerning the validity of Ainsworth's "strange situation" observational method (Ainsworth, Blehar, Waters, & Wall, 1969) for testing security of attachment. Main and Weston (1981) protest the restrictiveness of the three attachment categories of Ainsworth's method, since the forced choice may result in placing infants in poorly fitting groupings. Several authors have questioned whether the attachment studies are measuring attachment or some other variable, such as development of the reflective self in the child (Fonagy, Steele, Steele, Moran & Higgitt, 1991) or expressiveness of the child's temperament (Belsky & Rovine, 1987).

The choice of attachment behaviors used in many of the studies also raises questions. Morrison (1990) lists attachment behaviors for care-givers as "kissing, fondling, caressing, holding, touching, embracing, eye contact, and looking at the face," and for infants as "crying, sucking, eye contact, babbling, and general body movements" (p. 222). Cultural ideas of appropriate behavior may strongly influence fathers' physical expressions of attachment. Moreover, the infant's state and disabilities may modify his/her behavior (Chess & Thomas, 1982).

Some conflicting conclusions have been drawn from attachment studies. More sociable infant behavior has been more highly correlated with secure attachment with the mother than the father (Waters, Wippman, & Sroufe, 1979) and vice versa (Lamb, Hwang, Frodi, & Frodi, 1982). Whether mother-infant and father-infant attachments are independent of one another as Main and Weston (1981) assert, or highly correlated, as Fonagy, Steele, Steele, Moran and Higgitt (1991) conclude, is still a matter of debate, but both sides use the strange situation method to substantiate their claims.

So what can be gleaned concerning father-infant relationship development from the bonding and attachment studies? Two tentative suggestions based on bonding and attachment literature seem to be that early experiences of the father with his infant may make a difference in the development of the father-infant relationship, and that the father-infant relationship may influence some aspects of the child's life. Although bonding and attachment studies do at times suggest possible factors which might hinder bonding or attachment, such as parental stressors, family influences, and first impressions about the baby, the psychosocial processes involved in development of the relationship have not been adequately explored in bonding and attachment studies.

Relationship Studies From an Ecological Perspective

Some researchers have considered the father-infant relationship from a more ecological perspective, taking into consideration not only what is happening between the father and infant, but also the interaction of factors around and within the individuals. The central proposition for this type of study is that fathers and infants do not interact in isolation--they relate within a complex social context in which people, ideas, and other factors may all interact and influence relationships. The main influences on father-infant relationship development described by these studies are the wife, the father's learning, and the baby.

Fathers and mothers not only relate separately to the baby but also affect each others' relationships with the baby. Leventhal-Belfer, Cowan, and Cowan (1992) found that a father's satisfaction level about infant care decisions can be more influential on the mother's adaptation to motherhood than her own appraisal of the situation. Whether the reverse may be true for fathers' adaptation to fatherhood is unknown.

It has been documented that mothers influence the father-infant relationship development by serving as "gatekeepers" controlling interaction with the baby (Parke & Tinsley, 1981) or by forming a father-infant-mother triad in which jealousy, compensation, and competition may inhibit healthy relationship development with the infant (Pedersen, 1982). The physical presence of the mother also has been observed to negatively influence father's interaction with the baby (Thurman and Korteland, 1989; Clarke-Stewart, 1982).

Mothers also can influence the father-infant relationship through marital satisfaction or distress. Howes and Markman (1989), in comparing the findings of several studies of family relationships, conclude that marriage conflicts tend to negatively influence the parent-child relationship.

As the recipient of much information about the infant, the mother can either inhibit or foster the father-infant relationship through information flow. Stevens (1988) found that fathers were more likely to rely on their wives to supply them with child development information than to seek it from anyone else. Parke (1988) notes that one parent may direct attention to some attribute or behavior, which stimulates further interaction of the other parent with the infant.

A father's role and interaction with his infant may also be modified by the mother's employment, although the effect is uncertain. Study results have suggested that working mothers may become overly interactive with their children, perhaps to counteract the effect of their absence (Field, Vega-Lahr, Goldstein, & Scafidi, 1987); that employment status of wives makes little difference in their activity with the children but results in decreased interaction of fathers with the children (Zaslow, Pedersen, Suwalsky, Cain, & Fivel, 1985); and that fathers in dual career families perceived themselves to be more interactive with their children than they actually were (Crouter, Perry-Jenkins, Huston, & McHale, 1987; Zaslow, Pedersen, Suwalsky, Rabinovich, & Cain, 1986). Further research is needed to identify whether role and interaction modifications due to mothers' employment actually influence father-infant relationship development.

Learning may affect the father-infant relationship development. Several studies suggest that skills to enhance the father-infant relationship can be learned. Thurman and Korteland (1989) and Parke and Anderson (1987), in studies of parents of premature infants, concluded that some fathers may need assistance in learning to relate to their infants. Jones and Lenz (1986) found that the amount of stimulation that a father demonstrated in interaction with his child is directly related to his self-perceived level of competence as a father. Crummette, Thompson, and Beale (1985) found that fathers who participated in classes about babies and how to interact with them demonstrated more affectionate and caretaking behaviors than those who had not. Although Levant (1988) cites many examples of a growing trend to offer classes on fatherhood, little is known about what fathers would find most useful to enhance relationship development with their infants. Struggles of first time fathers to learn about normal child care are well documented, but learning about different aspects of care for succeeding children or children with special needs is not often described (Davis & May, 1991).

The infant may affect the relationship development. Jones and Lenz (1986) contend that infant states have a strong influence on father-infant interaction and that the responsiveness of the baby can set the tone for future interaction. Chess and Thomas (1982) and Kagan (1984) assert that the parent-infant relationship is highly influenced by the infant's temperament. Nugent, Yogman, Lester, and Hoffman (1988) found that infants who were alert, active, and slightly unpredictable were more likely to receive stimulation from their fathers than babies with more passive temperaments.

Summary and Critique

Most of these studies suggest that the father-infant relationship does not automatically happen due to biological mediation. They imply that multiple factors may influence relationship development, such as spousal effects, father's learning, and infant state or condition.

There is still much room for investigation about how other particular factors may influence the establishment of the father-infant relationship. For instance, in several studies, Cesarean section delivery (a frequent occurrence for babies with spina bifida because of hydrocephalus) has been highly correlated with both a higher and lower than usual level of interaction of fathers with their babies (Hwang, 1987). How the emotional state of the father might affect relationship development is largely unknown. Zaslow, Pedersen, Kramer, Cain, Suwalsky and Fivel (cited in Yogman, Cooley, & Kindlon, 1988) found that 62% of new fathers of normal babies recounted feeling sadness and/or disappointment in the early postpartum period. If this occurs after the birth of normal babies, then how might depression influence the father-infant relationship development after the birth of a baby with abnormalities?

Relationship Development With Children Who Have Handicaps

There is very little written about development of the father-infant relationship with infants who have disabilities. Austin (1991), in an extensive review of nursing literature from 1974-1989, found that studies of the effects of child disability on parent-child relationship were limited to mothers. A search of non-nursing literature also failed to discover studies directly related to the topic. Although no studies were found which directly addressed father-infant relationship development when the baby is handicapped, review of research about family stressors and coping when a child is handicapped suggested some possible areas to explore with the fathers in this study.

Several authors have hypothesized a process of adaptation when a child is born with handicaps; however, documentation of such a process is incomplete and sometimes contradictory (Burkett, 1989; Johnson, 1988; Scheers, Beeker, & Hertogh, 1984; Blacher, 1984). Downey (1981) tried to apply a pre-existing grief resolution framework from Kubler-Ross (1969) to the adaptation of families of infants with congenital defects, but found it inadequate to fully explain some of the variations seen. Burke (1989) documented evidence of chronic sorrow among mothers of children with spina bifida. Whether a similar situation exists for fathers is unknown. Farran and Sparling (1988) described periodic crises which reactivate grief processes and require readjustment for parents. Burkett (1989) proposed a "continuum of adjustment" in which the ability to accept the situation may vary at times, but the process continues. Ziolko (1991) and Blacher (1984), after extensive reviews of the literature, suggest that, although individual responses vary, there are common stages of adaptation for families whose children have disabilities. Hall (1994), however, in her study of 32 families, did not find any significant differences in the process of adaptation to parenthood when comparing parents of children with handicaps and parents of normal children. How grief and adaptation to a child with handicaps may affect father-infant relationship needs to be investigated further.

How the father's self-esteem is affected by having a child with a disability and how self-esteem may influence father-infant relationship development is also unclear. Relatively little has been written about how having an infant with a disability (other than mental retardation) affects a father's self-esteem. Tew, Payne, Laurence, and Rawnsley (1974) found that the self-esteem of parents of children with spina bifida may often be closely tied to the intellectual performance of their children. Cowan and Cowan (1987) found stress in the father role to be highly related to poor self-esteem. Hirose and Ueda (1990) documented decreases in fathers' advancement activities at work after the birth of an infant who has handicaps and suggested a possible loss of self-esteem.

Some possible psychological concerns for relationship development are posed by studies which compare reactions of fathers and mothers to having a child with disabilities. McConachie (1984) found that fathers were less likely than mothers to carry out prescribed play exercises with their children who had serious handicaps. Fathers have been said to experience less personal burden related to the child than the mothers (Weinhouse, Weinhouse, & Nelson, 1992). Both fathers and mothers of children who have handicaps have shown a higher frequency of mental illness than the general population, but mothers reported more psychiatric symptoms than fathers (Cairns, 1992). Whether fathers actually experience less mental distress or whether mental problems may go unreported is unknown. Dorner (1975) postulated that having a child with a handicap may make the mother more vulnerable to other psychological stressors, since the severity of the baby's condition did not always correlate with severity of depression. We do not know whether such increased vulnerability may exist for fathers of infants who have handicaps. Whether the mental condition of the father or his attitude regarding personal burden and responsibility concerning the child may affect father-infant relationship development is unknown.

Unmet expectations about the father's perceived role and the fantasized baby may influence father-infant relationship development. Although few researchers have described fathers' feelings specifically, numerous authors have documented parental distress from being denied their perceived role during their children's hospitalization (Burke, Kauffmann, Costello, & Dillon, 1991; Delight & Goodall, 1990; Charney, 1990; Barakat, 1991; LaMonagne & Pawluk, 1990). Davis and May (1991) describe a sense of cognitive dissonance and unpreparedness as fathers struggled with prior perceptions of fatherhood that they had imagined before the birth of their infant who has handicaps. The reality that a man cannot protect his family against serious difficulties, that he cannot provide all that may be needed, and that he may not know how to manage the multiple emotions and stressors associated with the care of a child who has disabilities may clash with his previous expectations of fatherhood (Davis & May, 1991). Very little is known about how a baby born with multiple defects who is not the perfect, attractive, responsive baby often described in the father-infant relationship literature (Anderson, 1994) influences the father's initial attempts to establish a relationship.

Little is written about what fathers of children who have handicaps find helpful to them. Social support has been identified by many authors (Havermans & Eiser, 1991;

Wallander, Varni, & Babani, 1989; Singh, 1990) as helpful for adaptation of mothers when a child is born with handicaps, although Kronenberger and Thompson (1992) point out that social support may provide problems as well as solutions. Very little has been written, however, about social support for fathers of infants with handicaps. Cairns (1992) found that fathers tended to internalize stress rather than seeking support from others, and that they evidenced more symptoms of physical stress than the mothers of children with handicaps. Davis and May (1991) described a sense of social isolation for fathers of children with handicaps because they felt that others probably would not understand their feelings, or be interested in their child's accomplishments, but would expect them always to be strong in order to support the mother.

Summary and Critique

In summary, although very little has been written about development of the father-infant relationship with infants who have handicaps, research related to family stressors and coping with a child who has disabilities does provide some suggestions of possible factors which might influence father-infant relationship development. Contradictory results from several adaptation studies contribute little to our understanding of how grief and adaptation may affect the father-infant relationship development. Factors such as grief, changes in self-esteem, mental health, and unmet expectations for fatherhood and the baby should be explored with the fathers of this study to determine whether these factors affect father-infant relationship development when the baby has spina bifida.

Brief Introduction to Spina Bifida

In order to have a preliminary contextual understanding of the situation for fathers of infants with spina bifida, it is necessary to look briefly at the current state of knowledge about spina bifida and the families of those born with this defect. The following topics will be addressed: incidence and pathology, severity and disability, and treatment of spina bifida and its associated anomalies. Then the research literature related to families of children with spina bifida will be examined for possible influences on the father-infant relationship development. For the purposes of this study, the broad term "spina bifida" is used because this seems to be a preferred term for parents, although all the babies in this study more specifically had a myelomeningocele.

Incidence and Pathology

Incidence of spina bifida ranges from around 1/1000 live births in most parts of the world to a high of 3-6/1000 in parts of Great Britain and in areas where people from Great Britain have extensively settled (Liptak, Bloss, Briskin, Campbell, Hebert, & Revell, 1988; McLaurin & Warkany, 1986). In 1989, it was the second most frequent reason for disability of children in the United States (Burkett, 1989). The Spina Bifida Association of Canada estimates that spina bifida occurs in 1:750 live births in Canada, with a higher incidence in the east and lower in the west (telephone communication M. Meldrum, Spina Bifida Association of Canada Research Committee Member, January, 20, 1994).

In spina bifida, formation of the neural tube during the fourth week of gestation is incomplete or abnormal and/or fusion of the vertebral arches during the third month is incomplete (Lavarack, 1980). Several theories of embryonic development have been proposed to explain the malformation, such as initial failure of closure of the tube, reopening of the tube at a later date due to fluid pressure, failure of development due to inadequate blood supply, abnormal attachments of the spinal cord, collapse of the ventricles of the brain during development, and faulty timing in development of parts of the nervous system (Tarby, 1991). Uncertainty of the mechanisms involved contributes to a sense of uncertainty for parents. The causes are also uncertain, although recent studies have linked spina bifida with a variety of possible causative factors, such as poor nutrition--particularly a lack of folic acid in the diet, genetic predisposition, consanguineous marriage, and prenatal use of some medications which control epileptic seizures in the mother (Lemire, 1986). Several other factors are under investigation, and this further contributes to parents' feelings of uncertainty.

Severity and Disability

The condition of the infant varies greatly depending on the extent and height of the defect. Some babies have only a gap in the bony structures of one or more vertebra(e), a condition called spina bifida occulta, and may have little or no nerve abnormality (Lavarack, 1980). Those with a meningocele have a portion of the spinal cord coverings (meninges) only protruding through the opening in the bony structures (Lavarack, 1980). In myelomeningocele, the spinal cord and nerve tissue also protrude through the opening (Lavarack, 1980). The most severe form of spina bifida is myelocele (or myeloschisis), in which the vertebral arches do not join, the neural tube does not fold, and the neural material is laid out in flat layers on the surface of the back (Lavarack, 1980). A sac containing the spinal cord and associated structures may be open or closed at birth and infection can be a serious threat to infants who have damage to the sac. Generally, the more unprotected the neural material, the more damage may occur to the spinal cord and the delicate spinal nerves which innervate many distant areas of the body. The level of the defect on the spinal column is very significant because, at each level, the nerves which are damaged or abnormal innervate different areas of the body (McDonald, Jaffe, Shurtleff, & Menelaus, 1991). Defects in the sacral area generally produce the least overall disability, lumbar area more, and thoracic area and higher the most severe disability (including possible paralysis of respiratory muscles, and problems with temperature regulation) (Rekate, 1991b; Alexander & Steg, 1989).

Damage to the spinal nerves may cause disability involving many systems of the body. Lack of nervous control may result in bowel and bladder control problems, and retention of waste products can cause damage to the bowel and urinary system due to over distention (Rekate, 1991b). Skeletal muscle innervation may also be defective, causing difficulties with movement, support, and muscle development (Mayfield, 1991). Oppenheimer (1986) found in her follow up study of 314 clients seen from 1964-1984 that 90% of those with high lumbar defects required wheelchairs, while 32% of those with mid level and 2% of those with low defects required wheelchairs. Secondary damage can occur from unbalanced forces of muscles pulling against developing bones resulting in deformities of the bones and dislocation of joints, especially clubbed feet and hip dislocation (Alexander & Steg, 1989). If sensory nerves are damaged, injuries may occur which go unnoticed because there is no sensation of pain (Dixon & Rekate, 1991).

Almost all those who have spina bifida also have faulty development of a portion of tissue at the base of the brain called the Arnold Chiari II formation (Griebel, Oakes, & Worley, 1991), which results in an obstruction of the circulation of cerebrospinal fluid produced in the brain. Untreated, this fluid can build up pressure in the brain and overexpand the ventricles causing brain damage and possibly death due to brain stem malfunction (Griebel, Oakes, & Worley, 1991). Seventy to ninety percent of individuals born with spina bifida have hydrocephalus to some extent (Rekate, 1991a). Most children with treated uncomplicated spina bifida demonstrate intelligence in the normal to low normal range, but exhibit particular learning disabilities, especially in mathematics, spatial perception, handwriting, information processing, and speech (Venes, 1986; Rekate, 1991b). Learning ability may be hindered further by hydrocephalus, eye muscle control problems, and, in some cases, by infections of shunts which can cause meningitis.

Treatments

Surgeries to close the back defect and to insert a shunt, which is a valve allowing the excess spinal fluid to drain from the brain into either the heart or the peritoneal cavity, are usually done within the first few days of life (Rekate, 1991b). Sometimes shunts can become blocked or an infection may occur requiring shunt replacement (Rekate, 1991b). The spinal cord may form abnormal attachments which can cause excessive stretching of the cord, called tethering, which also may require surgery (Banta, 1991). Operations may be done to correct orthopedic deformities such as abnormal development of bones due to muscle imbalances, tendency of hips to dislocate (Sherk, Uppal, Lane, & Melchionni, 1991), abnormal curvatures of the spine, and deformation of bones and joints with abnormal fetal and/or weight bearing positions (Alexander & Steg, 1989). Muscles which are well-innervated may be surgically divided and reattached at different points to redistribute muscle force and to improve posture and ability to walk (Menelaus, 1980). Bladder surgeries may also be required, such as augmentation, reconstruction or suspension of the bladder neck, implantation of an artificial sphincter, or, in rare cases, urinary diversion (Bailey, 1991).

Various other treatments may be required to maintain as close to normal function as possible. These children often require braces (may be lightweight fibreglass orthoses), orthopedic shoes, and special aids for standing, sitting, and moving about (Pomatto, 1991), including wheelchairs for the more severely affected individuals (McDonald, Jaffe, Mosca, & Shurtleff, 1991). Many of these infants require regular intermittent catheterization to control incontinence or to prevent kidney damage (Bailey, 1991; Sugar, 1986). Drugs may also be necessary to enhance bladder control (Bailey, 1991; Woodside, 1986). Stool softeners, suppositories, and other methods of bowel training (such as biofeedback) may be needed (Dixon & Rekate, 1991; Whitehead, 1986). A high fibre and low fat diet may be necessary to maintain adequate bowel function and to avoid obesity (Dixon & Rekate, 1991). Exercises are often prescribed to maintain muscle function, increase strength, promote bowel regularity, and prevent obesity (Dixon & Rekate, 1991; Williamson, 1987). As treatments advance, the prognoses for people with spina bifida becomes better, but much is uncertain about each individual's prognosis because so many complications can occur.

Effects on Family Functioning

Although the literature does not identify specific influences of the child's spina bifida on the father-infant relationship, there have been many studies documenting mothers' reactions, emotional problems, and physical problems with children who have spina bifida (Burke, 1989; Barakat, 1991; Kronenberger & Thompson, 1992; Singh, 1990; Wallander, Varni, & Babani, 1989). Family coping and social support have been measured from information usually supplied by mothers (Blitz, 1992; Loebig, 1990). Rarely researchers (e.g. Sproul, 1987; Cairns, 1992) have commented on some differences observed in the responses of mothers and fathers. Siblings of children with spina bifida also have been investigated (Loebig, 1990; Royle, 1990; Kazak & Clark, 1986; Pinyerd, 1983), but the study of fathers generally has been neglected.

Families of children with spina bifida may be affected by many stressors--relational, physical, financial, psychological, and social (Dorner, 1975; Singh, 1990; Worley, Rosenfeld, & Lipscomb, 1991; Pinyerd, 1983; Lewis, 1985). Increased arguing, development of physical or mental illness of the parents, decreased attention to other children, physical fatigue from lifting, and added expense for incontinence garments and supplies were documented by Richards and McIntosh (1973) as outcomes of those stressors. Long term effects on marriages have included increased marriage breakdown (Richards & McIntosh, 1973; Tew, Payne, & Laurence, 1974) as well as superior marital adjustment (Kazak & Clark, 1986; Martin 1975). Coping strategies in these families include strengthening of family ties, seeking information about the condition, and sacrificing to their own self detriment (Sproul, 1987; Van Cleve, 1989; Loebig, 1990). . . .

Not all of the studies of families of children who have spina bifida have reported negative outcomes, however. Menzies, Parkin, and Hey (1985) and Singh (1990) documented some rather remarkable adaptation and positive responses to challenges among the families of children with spina bifida, some of which had very poor prognoses. And Feetham (1980) found family relationships to be more important than the child's health situation as a predictor of family functioning.

Possible Influences on the Father-Infant Relationship

Some information can be gleaned from the spina bifida literature about possible stressors which may affect the father himself and thus influence the development of the father-infant relationship. Some of the stressors mentioned in the spina bifida literature are first impressions of the infant, anxiety, parenthood shared with strangers, and being required to make difficult decisions.

Little has been written about the effects of fathers' first impressions of the infant, though the appearance of the defect can be very shocking even to those who have seen this anomaly before. Regarding the health care workers' contributions to first impressions, Delight and Goodall (1990) found that, among parents of children with spina bifida, "47.5% were not satisfied with the way in which the news had been broken to them" (p. 7), and most of the parents expressed much appreciation for those people who brought their attention to things which were normal about their baby.

Macedo and Posel (1987) concluded that unresolved anxiety can interfere with parent-child relationships in families of children who have spina bifida. Questions about why this happened to their child add further psychological burden for the parents. Cultural beliefs and even superstitions regarding cause and effect relationships may contribute to anxiety and affect family relationships (Oyewole, Adeloye, & Adeyokunnu, 1985). Although genetic counselling is now readily available for most families in Canada, feelings of guilt and fear of producing future children with this or other associated neural tube defects may be an added stressor. The chances of having another baby with spina bifida in subsequent pregnancies is about five percent, which is 37.5 times the average incidence for Canadians (McLaurin & Warkany, 1986). After the birth of a first baby with spina bifida some choose not to risk future pregnancies and this may result in a particularly poignant grief, perhaps worse than that of infertility (Delight & Goodall, 1990).

The need to fulfil a parenting role for their children has been a recurring theme in studies of families of children with spina bifida. Parents have expressed a desire to fulfil a parenting role to their children even when the problems were severe enough that their children eventually died. Delight and Goodall (1990) found that, in general, parents who participated in the care of their baby coped more realistically and effectively with their baby's death, while those who participated little suffered long term emotional problems. Menzies, Parkin, and Hey (1985) found that children whose parents were allowed to care for them had better outcomes than those who were cared for by the hospital system even in very severe cases with little hope for survival.

Much anger has been documented among parents who felt they had not been allowed to fulfil a parental role with their baby. Scheers, Beeker, and Hertogh (1984) describe the sensation of "shared parenthood" between parents and medical personnel, and the parents' frustration that their children seem to be considered "children of science" whose bodies are "almost public property" (p. 121) because scientific intervention had allowed them to live.

Decision making has often been mentioned as an important part of the parenting role for parents of children with spina bifida. Ellis (1974) found that a large proportion of parents wanted to be more actively involved than they had been allowed to be in decision making regarding their child's treatment. Charney (1990) concluded that satisfaction was greatest among those parents who had some involvement in the decision making about care of their infants. Due to recent medical technological advances, parents may be required to make difficult ethical decisions. Prenatal diagnosis has introduced the possibility of parents having to decide whether or not to continue a pregnancy. Spina bifida may be diagnosed by ultrasound or by testing of the levels of alpha-fetoprotein in the pregnant woman's blood (Parke & Beitel, 1988). Parke and Beitel (1988) suggest that having the choice of whether to abort a defective fetus may help parents' later adjustment if they choose to continue the pregnancy because they feel it was their choice, and, thus, are likely to have a greater feeling of control of the situation and greater commitment to the child. Decisions about surgical treatment of infants born with spina bifida must also be made. Lorber (1971) proposed that criteria be adopted which would deny surgical treatment to more severe cases, but others have argued against this concept for ethical reasons (Bartoshesky, Young, & Scott, 1986). Recent advances in intrauterine surgical treatment for hydrocephalus (see Michejda, Bacher, & McCullough, 1986) make this another difficult area for possible decision making.

Summary of the Literature Review

Although none of the literature about fathers and their babies directly addressed father-infant relationship development when the baby has spina bifida, some areas of possible concern regarding father-infant relationship development were identified through the literature search on fathers and normal babies. The bonding and attachment literature suggests some potential difficulty for bonding and attachment of fathers and their infants who have spina bifida due to separation for medical treatments soon after the birth and possibly disappointing first impressions of the baby. Relationship studies from an ecological perspective suggest that the wife could either greatly help or hinder the father-infant relationship development in this situation through gate-keeper functions, through control of information gained from health care workers in the absence of the father, through affecting his role and interaction with the baby by her presence, and possibly through her employment status. The amount and type of learning about his baby and baby care which the father accomplishes and the condition and temperament of the baby may also influence the relationship development.

Factors which might possibly influence father-infant relationship development identified through the search of literature on relationship development with children with various handicaps were grief, adjustment processes, self-esteem changes, mental health, role conflict, unmet expectations, and supports for the father. The search of spina bifida literature yielded additional possible influences on father-infant relationship development related to changes in family functioning, early impressions of the baby, anxiety, parenthood shared with strangers, and difficult decisions. Investigation of other factors which may influence father-infant relationship development in this situation is needed.

CHAPTER III -- METHOD

Rationale for Choice of Method

This study was designed to further the knowledge base concerning father-infant relationship development when the infant has spina bifida by seeking to understand the fathers' perspectives about the process. Grounded theory was chosen as the research method. The method used for research should logically be determined by the research questions, the purposes of the research, and the current state of knowledge of the topic (Field & Morse, 1985).

The research questions require answers from an emic rather than an etic perspective (Osborne, 1976), which means that the fathers are the only ones who have the information which can answer these questions. Quantitative methods alone are generally inadequate to address many questions with which nursing practice deals, especially those concerning ideas, emotions, personal meaning, desires, and decisions--things which are difficult to quantify. Qualitative methods have been used effectively for many years to examine these areas in the social sciences. Qualitative methods also may be used to explore situations in the natural social, cultural, and historical context (Field & Morse, 1985).

The purpose of the study is to increase understanding of the process of developing a father-infant relationship when a baby is born with spina bifida. The premise that people generally act in accordance with the meanings they attribute to people, things, and processes is the basis for symbolic interactionism and guides theory development in qualitative research (Blumer, 1969; Morris, 1977).

As Munhall (1989) concisely explains, "One of the basic assumptions in grounded theory is that there are unidentified concepts or constructs that, if identified, will enable understanding and problem solving" (p. 172). She equates these concepts and constructs with the basic social or psychological processes which are identified as core variables in grounded theory research. Through analyzing and comparing the communications from several individuals, a beginning sense of trends, commonalities, and differences emerges (Seaman, 1987). These preliminary findings can then serve as a basis for further exploration and inductive theory building.

Because there is such a sparse and questionable knowledge base about the development of the father-infant relationship, grounded theory as presented by Strauss and Corbin (1990) is an appropriate method to use to develop "factor-isolating" and "factor-relating" theory to guide nursing practice (Dickoff and James, 1968).

Research Design

Nature of Sampling

Qualitative research samples are chosen theoretically according to appropriateness and adequacy as data sources rather than by probability or size criteria as in quantitative research (Chenitz & Swanson, 1986). Appropriateness is evaluated according to how well the sample is able to address the research questions, and adequacy is determined by the completeness of the data obtained rather than by the number of cases (Brink, 1989). Completeness of data is evident in dense description of categories and when repetition rather than new data is evident (Corbin, 1986b).

True theoretical sampling is to be guided by data analysis--beginning with those fathers who are likely to have general information to address the research questions and progressing to those who are likely to have specific information which in turn will clarify and refine theoretical elements as they are identified from the data (Strauss & Corbin, 1990). The very small size of the available population prevented true theoretical sampling of individual participants, and this is acknowledged as a limitation. Theoretical sampling of content areas was accomplished, however, since comparative analysis of interview data occurred throughout the data collection process and this guided the semi-structured questions in subsequent interviews. The sampling procedure employed was, therefore, purposive rather than theoretical (Field & Morse, 1985).

Recruitment of the Sample

Arrangements were made for two nurses who have regular contact with spina bifida patients and who are employed by two large hospitals to contact fathers of infants, to briefly explain the study procedure, and to query interest in possible participation. Only the phone numbers of those who expressed interest in participation were revealed to me. I followed the guidelines shown in Appendix A for actual recruitment of the subjects.

Spina Bifida Associations in the adjoining provinces were also contacted to query whether access to other fathers meeting the criteria might be available through their organizations. It was found that families generally did not join these organizations until their child was beyond infancy. No informants were found through this route.

The following criteria were established for inclusion in this study. Each father should be:

1) listed as father of an infant who has spina bifida,
2) living in the home with the infant,
3) able to speak and read English, and
4) willing to communicate about this topic.

Five men met all of the criteria. One of the fathers did not meet the second criterion but was included because I was advised by the hospital contact person that he was very active with the child, and that the separation from his wife was recent and probably temporary. After consultation with the thesis co-supervisors, this participant was included.

Sample Characteristics

A total of six men participated in this study. Demographic data were obtained from all of the fathers. Due to the very small size of the sample, however, listing of demographic data for each of the participants could potentially serve to identify them. Therefore, only a summary description of the demographics for the group will be given. Similar concerns led to a decision not to include a table describing the individual baby's disabilities in detail.

The men ranged in age from 23-42 years with four of the men being <30 years of age. Their wives were from 23-34 years old. Three wives were <30 years of age and one wife's age was unspecified. Four of the fathers were married (one separated) and two were in a common-law relationship. Two had completed grade 10, two grade 12, and one college (years of college were not specified). All of the fathers worked in either sales or service employment. Only two of the wives were employed outside the home. One family was in the lowest income category ($1-$29,999), three were in the middle ($30,000-$69,999), and one was in the high income ($70,000 and above) category for their total family yearly income. One declined to answer this question. None of the families were related to anyone known to have spina bifida.

All of the babies were male. On the first visit, the babies' ages ranged from seven weeks to nine months. Three babies had sacral level defects, two had lumbar level defects, and one baby's defect was at the thoracic level. Four of the babies had shunts in place and two did not (one baby's shunt had been replaced three times in the first few months of his life). The babies had been hospitalized from one to nine times before the study was finished, with most of them experiencing at least two hospitalizations during the first year of their lives. All were full term, singleton births, except for one who was a twin boy born prematurely at 32 weeks. All had a myelomeningocele. The severity of their disability varied from moderate, seen with the sacral and lumbar lesions, to severe with the thoracic lesion (including respiratory problems which eventually required use of a mechanical ventilator to assist the baby's breathing). Three babies also had clubbed feet and two had hip dislocation problems. Only one had required eye muscle surgery in the first year. The child with spina bifida was the first baby for two of the fathers, the second child for one father, and the third child for three of the fathers.

Data Collection

Data collection took place through 14 interviews occurring over a period of 11 months. Each of the fathers was interviewed twice. The length of time between interviews was three to 4 1/2 months, except for one who requested that his second interview be delayed until after his seasonal rush at work was finished. His second interview occurred 9 months after the first (when the baby was 14 months old).

The timing of the initial interview was originally planned to occur within the first three months of birth. The age range for first contact had to be expanded because of the small population, and recruitment was delayed in some cases until the hospital contact persons deemed that the families had overcome initial grief and were adjusting adequately. All first contacts were still within the infancy period (the first year of life) and were early enough to record the fathers' perceptions of early development of the relationship, without an excessively long period for processing of memories. The passage of time between the first and second interviews allowed for some change and, hopefully, growth of the relationship to occur, so that the process could be more effectively documented.

Conformity of age ranges of the infants was not attempted, since a greater variety of data could be expected by interviewing at different ages, and the small sample size dictated that all practical measures be taken to obtain as much data as possible from the available participants at their convenience. Because it was the process, rather than specific age-related developments, which was being examined, and because these babies may not necessarily progress through the developmental stages at the "normal" times, limitation to specific ages did not seem appropriate.

Semi-structured initial interviews were conducted using a topical question guide adapted with permission from Anderson (1994) (see Appendix B), which also included additional questions identified as possible areas of concern from the literature review. The participants chose the location and whether the interviews would be conducted by telephone or in person. All first interviews took place in each father's home. Interviews were opened with a grand tour question (Brink, 1989), asking each participant to talk about his baby. Flexibility was built into the process with the use of a variety of probing questions (see Swanson, 1986b) to clarify ambiguities and with the inclusion of a final question which allowed fathers to voice their own concerns which might not have been addressed previously. Demographic data were obtained (see Appendix C) to describe the sample.

For the second session, four of the fathers chose to be interviewed via telephone, while two chose to be interviewed in their homes. In the second interviews, relevant ideas from interviews with the other fathers were introduced for validation and discussion, as well as questions intended to elicit further information or clarification concerning each father's own previous statements. Each interview was tape-recorded and promptly transcribed verbatim by one of two typists who signed an oath of confidentiality.

In order to obtain the father's perspective without the influence of the presence of others, all interviews except one were conducted alone with the participant. One father insisted that his wife be present for the first interview in case he needed help with any medical terminology. She did not speak at all until the tape recorder was turned off at the end of the interview, but he sometimes looked toward her when using some medical term, as if he were seeking confirmation that he was using it correctly. Questions dealing with possible influences of the wife concerning the development of the father-infant relationship were covered in the second interview with this father (without the wife being present). Generally, the wife and any other children were in another part of the house during the interviews, although in some instances other children did enter the room and were promptly asked by their father to leave.

The interviews were quite informal. Although some semi-structured questions were asked specifically as written, many times the fathers brought up the topics themselves in a different order than presented in the interview guide. All areas of the interview guide were covered eventually. I encouraged the men to present their own thoughts and feelings without interruption, whenever possible, using guiding questions occasionally to focus on particular topical areas. As interviewing continued constant comparison of data guided formulation of further questions.

Data Analysis

A standard word processing program was used to facilitate data storage, labelling, duplication of selected portions to category files, indexing, and retrieval. Memos and field notes were kept throughout the process which facilitated theorizing. I first read all transcripts thoroughly while listening to the tapes as soon as possible after transcription. All areas of incomplete or inaccurate transcription were corrected or marked as unclear. Additional comments regarding tone of voice, appearance, gestures, and questions raised by the content were placed in brackets within the text. Ideas and questions which were generated throughout the analysis were recorded in capital letters and placed in sections at the beginning of each interview.

The data were then reduced as described by Corbin (1986a) by reading line by line and sorting and coding according to categories of similar ideas, domains, or concepts. Five initial themes were identified: being there, preparing, reacting, adjusting (thinking), adjusting (doing), and interacting. The themes were labelled and data associated with each category were compiled into files for comparison. Indexes were generated to facilitate examination of the content in the context of the interview as well as in category files. Data which fit into more than one category were cross-referenced as a cue for especially careful analysis to avoid redundancy.

Constant comparison of new data with previous information occurred throughout the process of data collection and analysis (Strauss & Corbin, 1990). The researcher alternated between inductive and deductive analytical processes as described by

Strauss and Corbin (1990). Categories were examined for goodness of fit of data within the parameters of the conceptual label, and refinement and revision of categories took place whenever the information indicated sufficient differences to require recategorization (Swanson, 1986a). Purposive sampling continued until categories were saturated with information, and new data which would suggest the need for further categories were no longer being added.

Axial coding as described by Strauss and Corbin (1990) was employed to examine possible relationships between category groupings. A core variable, "being there," was identified. The data were examined using the paradigm model of Strauss and Corbin (1990) involving "causal conditions, phenomenon, context, intervening conditions, action/interactional strategies, and consequences" (p. 99) as a guide for organization of concepts to begin to theoretically explain the process. A search for variations and negative cases occurred throughout the research process (Walker & Avant, 1988). Several models were drawn in order to graphically portray possible relationships and to raise questions for careful consideration. Memoing of ideas about possible connections facilitated the process. Repeated returns to the data resulted in an evolution of models.

After initial analysis of the interviews was concluded, a secondary review of the literature was undertaken to validate theoretical concepts extracted from the data and to further explore ideas which had emerged from the data. The findings were then taken to two of the original fathers for discussion and validation. Data from these discussions of preliminary findings also were analyzed. Beginning theory was identified and suggestions for future testing were proposed as a foundation for future research about the process of the development of a relationship between fathers and their infants who have handicaps. A summary report of findings was written and relayed to all participants as requested.

Objectivity, Reliability, and Validity

Kirk and Miller (1986) define objectivity, reliability, and validity in qualitative research:

> Objectivity is the simultaneous realization of as much reliability and validity as possible. Reliability is the degree to which the finding is independent of accidental circumstances of the research, and validity is the degree to which the finding is interpreted in a correct way. (p. 20)

Careful collection and preservation of the data in as close to original form as possible contributed to "consistency, stability, accuracy, and dependability" (Seaman, 1987, p. 317). This involved tape-recording of interviews, accurate transcription, use of field notes to recall aspects of the situation which might not be evident from the tapes, memoing to record ideas and questions, and immersion in the data during analysis by listening to the tapes while reading the transcripts. The records kept throughout the study ensured auditability so that other researchers could easily identify the "decision trail" used in the study (Sandelowski, 1986). All attempts have been made to relay the fathers' statements verbatim, but since one of the participants stuttered, and another had a habitual repetitive speech pattern, I deemed it necessary, for ease of reading, to remove multiple repetitions of words and habitual phrases which added little or no content. This resulted in an appearance of choppiness in the quotes at times, but allowed the content from the men to be relayed reliably and in a coherent manner.

Aspects of validity are somewhat different for qualitative exploratory studies than for quantitative studies, since there is a theoretical outcome rather than a measurement tool outcome. Content validity (Seaman, 1987) which reflects adequacy of sample is usually maintained by careful theoretical sampling for evidence of variation and negative cases (Walker & Avant, 1988). The very small size of the available population prevented true theoretical sampling which is acknowledged as a limitation of this study. Theoretical sampling of content areas and purposive sampling of the participants was all that was possible in this situation. Face validity of the overall research plan and the topical outline to guide interviews was evaluated by three experts in the field, two hospital research committees, the Spina Bifida Association of Canada research committee, the Alberta Foundation for Nursing Research, and a Spina Bifida Clinic team.

Using the fathers' actual words whenever possible contributed to validity, as did taking the concepts and constructs back to the informants for verification or clarification, since only the fathers could verify whether the data were interpreted correctly from an emic viewpoint (Kirk and Miller, 1986). Fathers B and C were consulted to validate or disagree with the findings. After reading the findings, they both supported the credibility of the study by acknowledging that the findings presented a very accurate description of their own experience (Sandelowski, 1986). One father commented that he "felt in tune with" the other fathers' statements, and that their words described feelings which he also had experienced but had not mentioned in his first two interviews.

Theoretical sensitivity which contributes to validity (as described by Strauss & Corbin, 1990; Glaser, 1978) was enhanced by extensive study of related literature, several years of professional involvement with new parents, and graduate work with parents of babies with congenital defects. Although there is debate concerning the value of doing an extensive literature review before attempting grounded theory, the scarcity of available literature which directly applied to the research questions and careful bracketing of any initial assumptions helped to maintain objectivity.

Because the gender of the researcher could influence the study (Daly, 1992) and possibly threaten validity, I acknowledged to the participants the possible "foreignness" of their experiences as fathers in comparison to my own as a mother. This heightened objectivity, compelled flexibility in the interview process with careful clarification of ambiguities, and resulted in full and rich explanations from the fathers. The process involved in constant comparative analysis used in grounded theory research (Strauss and Corbin, 1990) further sharpened sensitivity to unclear statements. Although lack of willingness to share emotionally sensitive information with a woman was predicted, I found the men to be very open. Both tears and laughter were not uncommon in the interviews as the men seemed eager to share what one man described as something "nobody ever asked about before."

Ethical Considerations

Ethical clearance was obtained from both hospitals and from the University of Alberta. Participants were informed of the research plan, that there were no known risks and benefits to participating, that I was not an employee of either hospital or Spina Bifida Clinic, and that participation or nonparticipation would not affect their care. They were told that they could decline to answer any question and could drop out of the study at any time. They were informed of procedures intended to ensure anonymity and confidentiality and they signed a consent form written at grade 8 reading level (as determined by Rightwriter software) for the northern half of the province and at grade 10 reading level for the southern half of the province. This discrepancy in reading levels was due to different requirements for wording for the ethics review committees of the two Universities which regulated research in their associated hospitals (see Appendix D). Each father was given a copy of the consent form to keep.

Names and identifying data, including names of hospitals, were deleted from the transcripts and replaced with code designations to assure anonymity. Only I knew the identities of all of the participants. The hospital designated contact persons knew only the identities of the potential participants whom they had contacted. Permanent storage was secured with consents and code lists being stored in one locked file, and transcripts and notes being stored in another locked file. All study materials will be destroyed after 7 years, except the consent forms and code lists of the southern participants which will be destroyed 2 years after the age of majority of all the involved children (as required by the affiliated hospitals in the southern portion of the province).

The participants were informed that quotations from their interviews might be used for educational and research purposes and might appear in publications or presentations at conferences, but that anonymity will be maintained. They also were informed that their interviews might be used for secondary analysis at a later date if ethical approval was granted.

CHAPTER IV -- FINDINGS

The purpose of this study was to describe the experience of father-infant relationship development when the baby has spina bifida, and to identify factors which helped or hindered that relationship development. The goal of the grounded theory analysis was to identify the basic social psychological process (BSPP) described by the fathers and to develop beginning theory related to the process. The BSPP which emerged from the data (see Figure 1 below) was "being there for my child -- no matter what." This BSPP may sound somewhat one-sided to be describing relationship development because it only appears to require effort from the father in order to be accomplished. The context of uncertainty, however, may justify this description of the process. Initially these fathers were uncertain whether their babies would ever be able to relate to them in the manner which could be expected of a normal child, but they earnestly desired to give their very best to this child, no matter what the outcome might be. Being able to successfully be there for this child in the way the fathers desired involved four subprocesses: a) committing himself to being the father of this child, b) getting to know and be known, c) looking beyond the situation, and d) finding meaning in the relationship.

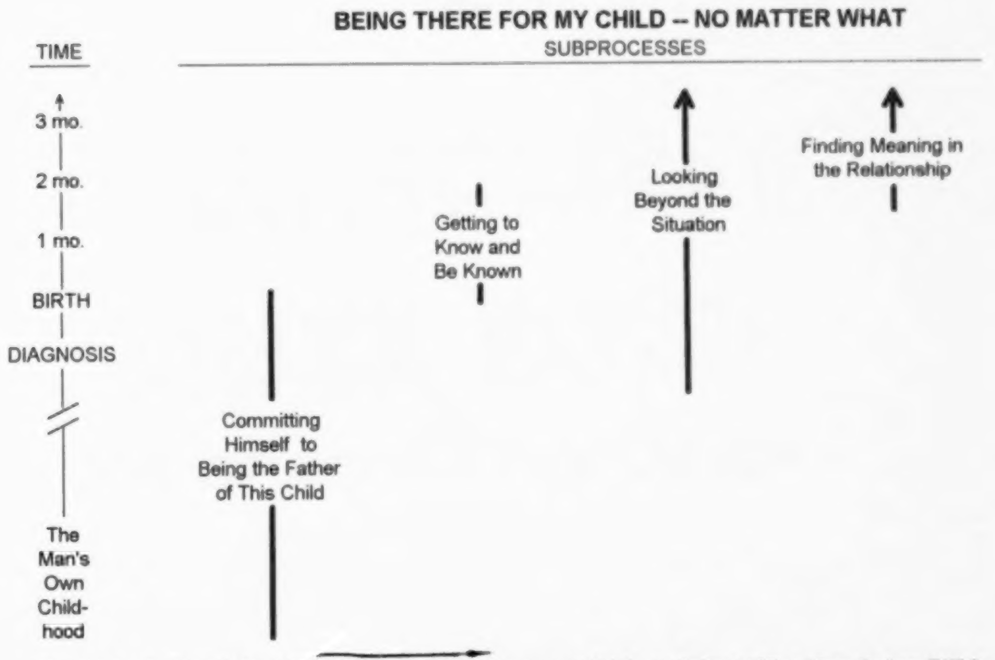
BEING THERE FOR MY CHILD -- NO MATTER WHAT
SUBPROCESSES
TIME
3 mo.
2 mo.
1 mo.
BIRTH
DIAGNOSIS
The Man's Own Child-hood
Committing Himself to Being the Father of This Child
Getting to Know and Be Known
Looking Beyond the Situation
Finding Meaning in the Relationship

Figure 1: Father-Infant Relationship Development With an Infant Who Has Spina Bifida

In this chapter, I will first present excerpts which illustrate the characteristics of the core category of "being there for my child--no matter what." Then, I will address each of the four subprocesses of development of the father-infant relationship. Factors which helped or hindered the development of the father-infant relationship will be introduced within the description of the subprocesses.

"Being There for My Child--No Matter What"

These fathers described "being there" as a very important responsibility for fathers and as a way of relating to their child which involved permanence, unconditionality, absent-presence, and (hopefully) reciprocity. Many comments from the fathers indicated that they measured their importance and their success as a father by the extent of their being there for the child. Their comments clearly indicated that this kind of being there is also permanent and ongoing.

> **My important role--I guess it** [is] **always being there for him if he needs me.** (D-2)
>
> [What's really important in being a good father is] **just being there for your baby**. (F-1)
>
> **I've been there for everything he's wanted, everything he's been through...thick and thin, and I'll be there for the rest of my life. I think I have possibly been the best father he can ask for.** (C-1)

The permanence and unconditionality of "being there" in this way was further emphasized by comments which indicated that they intended to be there for any of the child's problems or needs even if remarkable effort was required of the father to do so.

> **Being there is for anytime, anything--like if [he's] sick or say skinned his knee or things like that, like even if, say he gets into a little bit of trouble at school or whatever--you are there. That's the way you build the trust.** (D-2)
>
> **I want him to know that we will always be there for him no matter what.** (F-1)
>
> **I'll be there for him no matter what. If I have to fly, jump over mountains, I'm going to be there!** (E-1)

Being there in this way involved much more than physical presence and could even transcend physical separation. Some of the men expressed appreciation for how their own parents are still "there for [them]" even though they live far away. One man described a process of establishment of trust which allowed absence without the diminishment of the sense of "being there."

> **I think that once they know that somebody does care and that person will support them...they are able to say, 'Even though that person's not there, that doesn't mean that they've stopped loving me.'**(B-2)

The fathers hoped that being there in this manner would result in a reciprocal relationship. When asked if the desired relationship involved the child also being there for the father, the answers indicated such an expectation.

> **Boy, you sure hope so!** (A-2)
>
> [Being there for each other]--**that's the whole point of it because it makes us stronger**. (D-2)
>
> **I just wanted to be more or less...a good father to be there for my child and my child to be there for me.** (C-1)

One father even classified "**being there for other people that are there for you,**" as part of being smart--"**an overall life sense smart**" that he expressed hope his own child would develop. (C-1) The importance of a reciprocal "being there" in the relationship will be further illustrated in the section entitled "Finding Meaning In the Relationship."

In summary, these fathers considered being there for their child as an essential part of being a good father and they judged themselves by the extent of their fulfilment of this role. By being there for their child they hoped to develop a relationship with their babies which would be very deep, lifelong, and unconditional. It was intended to be mutual and to continue even when distance would separate the father and child. The fathers so strongly believed in the importance of this relationship that they were willing to work hard and to sacrifice. In order to be there fully in the manner they wanted to be, the fathers experienced four subprocesses--each of which demanded much effort on the part of the fathers.

Committing Himself to Being the Father of This Child

Prior to the Prenatal Diagnosis

The first subprocess which helped the father to be available both emotionally and physically for this baby involved the man's commitment to being a father. The Concise Oxford Dictionary (1990) defines the verb "commit" as "[to] pledge, involve, or bind (especially oneself) to a certain course or policy" (p. 228). These definitions imply a deliberate choice of involvement.

Although not all of these pregnancies were planned, all of the fathers expressed a desire to have a baby, and all but one father claimed to have a stable relationship at the present time with his spouse. Four of the men had other children, and they commented that most of the process of commitment to being a father had occurred for them prior to this particular pregnancy. Committing to this child for the experienced fathers was not as complex as committing to the first child and only involved being willing to take on a father role with an additional child. Some fathers, however, described their emotions and thoughts associated with making that initial commitment toward their first child. The men described two parts to this subprocess. One consisted of internal action and included questioning how fathers should relate to their children and fulfil their role, and how they themselves measured up to their fatherhood ideals. This questioning about his potential adequacy as a father resulted in some ambivalence for one man during the pregnancy, which resolved shortly after the birth. The other part of this subprocess involved external action, which included some rearranging of their lives in order to prepare to be there for their child as the kind of father they wanted their child to have.

Internal Activity

For most of these men, thinking about fatherhood began in their own childhood. The fathers spoke about their own experience (or lack of experience) as a child relating to a father figure. Two spoke with gratitude of a strong and pleasant relationship with their own fathers when growing up, which made modelling after them easy.

> **I wanted to be like my father, absolutely.** (B-1)

> **My dad was always there** [even though he and the mother were separated--he lived in the same town]**....He took really good care of me....Yeah, play soccer, baseball, swim--you name it--we did it. We even worked together when I got older because he was a carpenter.** (F-1)

The remainder of the men came either from separated families or (for one man) a family with an alcoholic father, and the experiences with their fathers were lacking or unpleasant. Anger, hurt, and feelings of helplessness were evident in some of their statements.

> **I went camping with my friend's family, their fathers. I seen how their father/son relationship was....But when you see that, sure you miss it, but what can you do? You can't really do much. You got a mother. Your father doesn't want to have anything to do with your life, so, it's just that is the way it is going to be.** (C-1)

> **Hopefully I'd not be like my father...He'd take us out--he'd be drunk. He'd go hunting--he'd be drunk. He'd take me and go golfing when I was old enough and he'd be drunk. That's the last thing I wanted to be--the very last thing.** (E-1)

When they considered their childhood experiences of relating to a father to be inadequate, most of the fathers described thinking about how a father should be. Some looked at other fathers or their mother for role models in order to choose their own fathering style--often emphasizing the activities which they felt were lacking in their own childhood or avoiding the actions they thought were wrong.

> **I had one friend that his parents were always together and we used to go sailing and stuff in the summertime.** [I: So you sort of wanted to model like him?]...**Sort of, yeah, but just do my own thing, but be my own person....I guess I always wanted to be the Dad I never had.** (A-1)

> **I didn't really have any good [upbringing] from any fathers--my mom and dad were divorced early....But I can't take anything away from my mother because my mother did for me what my dad wasn't there to do for me....The way...I'd be** [as a father] **is kind of the way my mother was to me--kind of old fashioned...lots of rules--things that are tough to live by when you're a kid, but when you grow up you learn to have respect for a lot of people.** (C-1)

> **My father wasn't really there for me very much. He was an alcoholic and always beating my mom and being rough on us kids and I got two younger brothers and they grew up really torn apart....I don't know, that's an escape route, I think for him. For me, I'd just sooner be there and be myself and be alert to teach [my son].** (E-1)

> **I learned** [how to be a father] **strictly on my own....Actually, I'm still learning....I used to get abused a lot when I was a kid. I sometimes have those flashbacks and I don't really believe in spanking my kids....I don't figure that they should be raised the way I got raised because there's no sense in that.** (F-1)

Only one of the men (one of the two first-time fathers) described ambivalence about the idea of fatherhood at first.

> **[Prenatally, I] thought about being a father and thought of not being a father. You know having a child just takes away a lot of freeness we have. We had to adjust to that ourselves - for me, myself, I kind of have another life when I'm working out of town and then I come home and it's kind of - I'm pulling out my hair until I get used to it. I think I got used to it rather quick, though....I just love it.** (E-1)

Cowan (1991) defines the transition to fatherhood as more dependent on changes within the father than with the actual date of birth. This seems to provide a plausible explanation for the length of time it took for fatherhood to seem "real" for one man.

> **It took a little while. I just couldn't believe that she's carried it for nine months and we have a little baby. We have an intruder in our house now. Things have to change....I think it took probably two months and it sunk right in and I just...couldn't have been any happier then.** (E-1)

Another internal action described by some of the fathers involved imagining how it would be to have a child/or children. Their imaginary children all seemed to be older than infancy--at an age when they could enjoy fun activities. None of the fathers described his imaginary children as disabled in any way, although one man experienced some fears about the possibility of handicaps before deciding to start a family.

> **When you are a kid and you are always playing house and stuff. I sat down and thought about it when I was a kid. You can't really say it was serious thought when you are only six/seven years old, but when you sit down and think about being a father you'd think like I just finished going swimming I would like to have my boy swimming. I play baseball and I am into sports and I want my son...(or baby girl-no matter)...to do what I like to do...But when I was a kid, yeah, I sat down and thought about lots of good things for my boys.** (C-1)

> **When I was a kid I always promised myself I would always go out and play with my kids....always being there when they needed me....I always wanted them to make sure that if they were ever in trouble or whatever they'd make sure they phone me.** (A-1)

> **When you are an expectant father you always like to think that you are going to have a healthy baby.** (C-1)

External Activity

As the time of birth drew nearer, the men compared themselves to their fatherhood ideals and some of them decided they needed to change. This resulted in not only attitudinal changes but also external manifestations of those changed attitudes. Most of the fathers described various aspects of growth from the beginning of the pregnancy such as becoming "more mature" and "settling down." One first-time father described taking better care of himself because of his family relationships.

> **I think I've gotten quite a bit more mature, more responsible....I don't think I'm as free and willing to go out and play and get in an accident. I'm looking out for myself a little bit more. You know when you're walking through traffic you don't just run across the road, 'Oh, there's cars coming, I can make it.'...I have something to look forward to coming home for [my wife], and now it's even more because I've got a baby.** (E-1)

Some of the men chose to make lifestyle changes so that they could be the kind of father they wanted their child to look up to.

> **I couldn't party as much. I had to make a decision.** (F-1)

Influencing Factors

Friends both helped and hindered the process of committing to fatherhood for the first-time fathers. Some of these fathers learned parenting skills and attitudes during the pregnancy from friends whom they considered to be good fathers.

> **I didn't have any teacher help or anybody to show me how to be a father besides a couple of friends that have had a child and tell me things to look out for and what to do and not to do.** (C-1)

It is interesting to note that Father C recounted a continuation of this helpful relationship with friends as he adjusted to fatherhood after the baby was born.

> **Sometimes you pick him up in your arms and there are times when he won't settle down for a long time. It's like, 'Oh, my God!' You talk to your friends about it and they say, 'Well, just take a pill--it's a child thing, you know--kids do that.' [laughing]** (C-1)

Friends could, however, adversely affect the father as he was committing to being a father. Some friends frightened one father by overemphasizing the responsibilities of fatherhood. After fearfully committing to a fatherhood role which he perceived to be loaded with responsibility, Father C described his delight in discovering that fatherhood was actually fun.

> **At first you are scared about having a child because you don't really know anything about it, but once you have a child the fright is gone because you learn...that it is fun raising a child. It is not just responsibility [after] responsibility...like everyone says it is.** (C-1)

Another first-time father concluded that some of his friends adversely influenced him in terms of the kind of father he wanted to be, and so he avoided them as part of his lifestyle changes.

> **I think I've even lost a few friends there....It's all for the better for me. Because they were kind of a bad influence--together we were a bad influence on certain things....Even my little brother--we were really close. We hung around and we got into a bunch of bad stuff and I didn't even hang around with him [after deciding to change because of the baby]. I said, 'I don't even want to talk to you or hang around with you because I got out of being the bad guy.' And next thing you know, my brother is coming back around and he's straightened himself out...and we've become best friends.** (E-1)

Summary

Committing to fatherhood of a hopefully normal child involved internal and external activity which resulted in clarification of the man's ideals about fatherhood, planning about how he wanted to be as a father, and changing in order to become the kind of father he wanted his child to have. Friends could either help the process of committing to fatherhood through offering information and advice, or they could hinder the process by negatively influencing the father. At this point, friends were the predominant sources of information and feedback for the fathers. The men expressed no need for professional help and seemed to view committing to fatherhood as a normal life process, using phrases like **"It's (a) part of life"** (A-1; & E-1).

Though these men did not specifically describe making a commitment, they spoke of their goals of fatherhood using phrases like **"be the best father I could be"** or **"give [my baby] all I can**," which clearly seemed to indicate that they had committed to meeting high standards of fatherhood which they had set for themselves.

After the Prenatal Diagnosis

After the prenatal diagnosis of spina bifida, however, the fatherhood they had imagined and committed to became very uncertain, and emotional turmoil was often recounted. Uncertainty about the cause of the abnormality and the outcome of the pregnancy left the fathers feeling like they had little control over the situation, which resulted in feeling varying degrees of helplessness. Furthermore, loss of the "fantasy child" each man had imagined resulted in feelings of sadness.

Trying to find the reasons for the abnormality initially resulted in feelings of guilt and blame, but this reasoning was inadequate to fully explain the situation or to combat feelings of helplessness. The incomplete knowledge of causation allowed the fathers to conclude that it is no one's fault--it just happens.

> **[I was thinking] maybe I did it or maybe it's because of my genes or maybe it's because of smoking drugs or drinking beer....But it turned out it was nothing--it just happens, you know.** (F-1)

> **We took it hard, thinking that the wife did not take vitamins and stuff--all that--but that doesn't have really nothing to do about it.** (C-1)

After rejecting the feelings of guilt and blame, the fathers and their wives could better address things that they could do, such as supporting one another.

> **We didn't blame each other because we didn't know. And my wife was worried that I was mad at her for what happened to him. It's nobody's fault what happened....The best thing we can do is to pull each other together and be strong because we have to be, not only for ourselves, but for the baby.** (D-1)

For four of the men, the diagnosis occurred during the pregnancy, which meant that they had months to mourn, prepare, and worry before the child was born. Although Fathers A and C expressed appreciation for having been given information to prepare them, all of the men were left with very bleak prognoses and much uncertainty about what fatherhood would hold for them.

> **My wife was four or five months pregnant I guess...so I was warned for it, which I really believe that's the way it should happen....[But] those guys had us just scared so we didn't know what to expect. You know he has a hole in his spine and you don't know. He could be born with no legs, right, who knows?...We just didn't really know what to expect.** (A-2)

> **Okay, we're going to have the baby, celebrating and you're happy and then they tell you about what's wrong and that bursts your bubble....We found out about halfway through the pregnancy by ultrasounds and all that he might have problems with spina bifida....We went on till...about a good six months...of preparation....It kind of got me going, 'Oh no! Oh, no!'.** (C-1)

> **The ultrasound operator came and got one of the doctors to come in, and he...basically created an image of a child born who would be extremely retarded, extremely deformed, extremely challenged, to put it mildly, just to survive....I think we had just ended the twenty-third week...so they were basically leaving us for approximately three months with this very negative, worst case point of view.** (B-1)

The worst part of the pregnancy according to these fathers' descriptions was the waiting. This long period of uncertainty not only confused their evolving ideas of what fatherhood of this child could mean for them, it also put a strain on their marriage relationship, which for Father F involved making a further commitment to the husband-wife relationship, as well.

> **The waiting game--the six months [before the birth]--sure a lot of things go through your head for the six months....There would be some fighting, but you know that's due in every relationship to let out the stress and all that. But, other than that, after he was born that has been fine. It was just like a little bit before he was born--like the curiosity building up--like how is he going to be when he comes out? Hurry up and come out!** (C-1)

> **When she was eight months she went for an ultrasound....They made him sound like he was going to be a monster....It was almost like a nightmare waiting to happen....I wasn't sure whether he was going to live or die.**

> **Neither were the doctors. They weren't sure about anything then....That's almost like waiting for judgement day or something....You know it's going to happen and you know it's going to be terrible, but you don't know exactly. So we did not know what to expect, but [my wife and I] made a pact with each other that we were going to stick it out no matter what.** (F-1)

Combatting Helplessness: Developing a Helpful Role

As feelings of helplessness increased, the fathers realized the absolute necessity of coping with this situation.

> **After we found out about [it], like there's not really any more hope that you're going to have a kid without spina bifida. You know about it. You've got to deal with it and put it behind you because the more you're going to sit and dwell on it--it's going to be one hell of a long life for you and your family.** (C-1)

Doing what they could do to help was mentioned many times by each of these fathers and it seemed to give them some sense of control over the very uncertain situation. The Concise Oxford Dictionary (1990) defines the verb "combat" as: to "oppose, strive against" (p. 224). This term fit many of the fathers' actions in response to the uncertain situation regarding their child, as they often used terms which implied active resistance or fighting to describe their actions to counteract feelings of helplessness.

> **It was just the feelings. How do you pack the feelings away when you know your kid is going to have that? How [are] other people are going to react to him because he has it? You've got to build up the fire inside you stronger because you know you've got to fight for him like he's got to fight for himself, too.** (C-1)

One of the fathers clearly illustrated an attitude of refusal to accept the idea of being helpless in this situation.

> **I guess you could say that I've never been one to accept a straight off negative situation--say you have no ability to change this. Sometimes that is the case, but that is not very common that that's the case. Usually you have some degree of influence, and it's a question of what you can do and is it as bad as what people are saying?** (B-1) **I'm used to taking problems on myself and solving them.** (B-3)

The other fathers expressed varying levels of confidence in their abilities to perform some actions which would help their children.

Developing a helpful role in the situation became a quest for these fathers. The Concise Oxford Dictionary (1990) defines "helpful" as "(of a person or thing) giving help; useful" (p. 548), and "useful" as "producing or able to produce good results" (p. 1352). Because the physicians had given them such uncertain and negative forecasts about their babies, the men wondered what they could do to perhaps change the situation or, at least, help to bring about the best outcome for their child. They realized that they needed information about spina bifida and related anomalies in order to know what was best to do, and they wanted the information then--not later after the baby's birth. As one father put it, "**I figured that** [information] **would help me help him** [my son]." (C-3) As the men sought to become more knowledgeable, health care workers were sometimes helpful. More frequently, however, health care workers were reported to have hindered the fathers in their prenatal search for useful knowledge by giving information which was often inadequate, overly negative, or outdated. None of the families was referred to a Spina Bifida Clinic until some time after the baby was born. Father C described his pediatrician as very helpful prenatally and knowledgeable about spina bifida. Father B, who had declared his unwillingness to accept being helpless or useless in this situation, detailed a long and desperate time of searching to obtain the information he needed in order to know whether the situation was as dismal as the physicians had described.

> **Well, first of all I started off by going to book stores just...for myself....Well, there's no particular books that deal with this topic in say Cole's and Smith Books and so on. There were books that had like a page or two of information, versus if you had a child with Down's or something like that, I mean there were complete books on that....We were desperate to find out more to see, 'Is it really this bad?'** (B-1)

Feelings of frustration occurred for one father as he was strongly urged by the physicians to just opt for abortion. To the father, it seemed as if the physician was not willing to try to help the baby or to help the father to help the baby.

> **They were basically saying, 'You know, a lot of people at this point would look at having a straight abortion and just walking from the circumstance.' I guess it's pretty much like the ultimate in the disposable society. 'This child is not perfect so we're just turfing him.'** (B-1)

The other five men said that abortion had not been mentioned to them by the physicians, but the comments from some of them implied that they also had thought about abortion but had judged it to be morally wrong and an abrogation of their duty as a father. They spoke of reflecting on the meaning of perfection, kinship, and responsibility as a father, which resulted in claiming this baby.

> **The thing that got me about just about everything that I heard and everything that I read was that if a child is not born perfect, 'Why would you want this child?' failing to take into account that very few things are perfect to start off with and anything can happen to any child any day.** (B-1) **In my mind it was just like an automatic...this is my child and it's my responsibility and I'm going to do the absolute best that I can for him.** (B-2)

> **I really am offended and I really don't respect people that have abortions. You're responsible enough to have sex. You should be responsible enough before having sex knowing what the consequences are....Family comes before anything in life....It wasn't a mind makeup--[it was] like we're going to have [this baby]--no matter what.** (C-1)

> **Even before he was born...we didn't even have to decide because he is our baby, you know....It's really frustrating that a lot of people would just give up on their kids or something because they're the ones who decided to make that baby and they should stick by it.** (F-2)

Coping With Sadness: Social Support

Another feeling which threatened the father's ability to fully commit himself to being the father of this child and to prepare to fulfil his desired helpful role was sadness. This resulted from the sense of loss of the child and the dreams of fatherhood which they had imagined. Most of the fathers talked about some period of grieving which they experienced after the diagnosis. Others' concern for the father and attempts to comfort helped some of these men to cope with feelings of sadness. One father described his experience of social support during his grief.

> [The news of the abnormality] **was kind of like a big kick in the face....It kind of just ripped your souls right out.** (C-3) **We had that one hard day sitting down with the family and friends and stuff and that all just made everything better--opening up, talking, crying, whatever you have to do, and other than that everything was going....But, I guess, if it wasn't for friends and family, we would kind of be lost right now.** (C-1)

Father C also implied that sadness might have been a recurring feeling if the medical community also had not offered their support during this time of grief and preparation. His perception was that the support was offered because the physicians recognized his and his wife's commitment to this baby.

> **We were there [at the doctor's office] every week, so we didn't have time to sit down and...dwell and get sad....[The doctors decided] 'Well, since they're showing that they want to fight and go on like with this child and stuff, we will help them....We'll do everything we can.'** (C-1)

Not everyone could accept social support at this time, and two of the men chose to be alone. One spoke about an anguish-filled week between the prenatal diagnosis by the radiologist and the appointment with a pediatrician who finally explained a bit about the condition of their child.

> **I felt terrible. I knew my son was going to be born sick and, like, I just couldn't stand the thought of it....I don't know, I just got this feeling of [my wife] and I being alone...really alone.** (F-1)

Although he did acknowledge that friends tried to comfort him, he described emotional turmoil which seemed to prevent him from being able to accept the comfort. He attributed his decision not to seek social support to a strong self-perception of independence.

> **I didn't need anybody else because I'm an independent person and also his mother is, so we never really ever depended on anybody and we never ever wanted anybody's remorse.** (F-1)

His attitude about his own independence seemed to have changed drastically later, however, as he realized that he did need others to help him cope with his feelings. His advice to other fathers was to realize that they are not alone.

> **I'd just like for all the fathers to know that they are not alone--that there's organizations out there, there's counselling. I felt that we were the only ones with a son like this, but it made me feel a little better knowing that we were not the only ones who are going through it--it helped [us] to cope a lot.** (F-1)

The other father who chose isolation also described emotional turmoil saying he and his wife were "**beyond any state of shock**" for several weeks after being advised that they should just abort their twins because a stillbirth or premature labor was likely anyway. He cited uncertainty about the pregnancy outcome as one reason for their isolation from others during this time of grieving.

> **Well, for whatever good or bad reasons we decided, both my wife and myself, after talking this through, that we weren't going to spend a lot of time telling people of the circumstance at this point...until we knew what were facing and what it was going to be like. We were basically told that there was a good possibility that [he] wouldn't be born alive that [he] would be stillborn.** (B-1)

Father B, however, recounted an insightful example of social support which really helped.

> **At one point after we had come home (I guess it was [from] one of the ultrasounds or something), our neighbors next door were saying, 'Hi, how's it going?' [My wife] burst into tears and they recognized it wasn't time to go on. But later on, they're both doctors...so we had told them what the situation was, so they [gave us] some research [information].** (B-1)

These neighbors seemed to give him exactly what he needed at that point. They told the father about two cases which had seemed hopeless, but which had turned out well, mainly due to the actions of those childrens' parents. This news gave him hope that he also might have a helpful role in his own son's life. This episode seemed to break the silence for this father. After this incident, he shared information about his baby's situation with others who also provided social support.

Summary

In summary, after the prenatal diagnosis, the fathers felt very unsure of what being the father of the child would hold for them and they experienced emotional turmoil. They realized that they needed to cope with the situation, and did so by developing a helpful role--as a father who was prepared, willing, and able to effectively help this child. In order to be able to carry out his helpful role, the fathers sought more knowledge about spina bifida and associated anomalies--both with and in spite of the assistance of health care workers. Examination of their beliefs about perfection, handicaps, kinship, and responsibility as a father helped them to claim this baby as their own, rather than choose a therapeutic abortion. Sadness also threatened the father's ability to fully commit himself emotionally to being the father of this child and sapped his energy to prepare to fulfil his desired helpful role. Social support helped some of the fathers to overcome sadness. Some other fathers, however, initially were unable to accept social support due to self-perceptions of independence or uncertainty of the pregnancy outcome.

The internal and external activity that the fathers completed prior to the prenatal diagnosis as well as the actions which they undertook to cope with helplessness and sadness following the prenatal diagnosis helped each father to commit himself to being the father of this child--the first step toward being there for the child--no matter what.

Getting To Know and Be Known

The Concise Oxford Dictionary (1990) defines "relation" as "the existence of or effect of a connection, correspondence, contrast, or feeling prevailing between persons or things" (p. 1013), and "know" as [to] "be acquainted or friendly with (a person or thing)" (p. 655). In order to establish a relationship, it is necessary for the parties to know one another. Each father wanted to know all about his baby and wanted to be known by his baby. Intense curiosity had been building up throughout the pregnancy concerning what the baby would be like including his condition. Getting to know the baby initially involved being there to meet and greet the baby. Relating to the baby as the FATHER--the person who is there to protect, comfort, and spend time with the baby--was a vital part of "being there" for these fathers and, moreover, was a way for the baby to get to know his father and his intentions.

Being There to Meet and Greet the Baby

Emotional Roller-coaster

The fathers in this study described intense emotional highs and lows associated with the birth of their babies. Some of the fathers described intense excitement.

> **[The birth was like] probably, I don't know, a roller coaster ride, or something....you just get the emotions and your adrenalin pumping when it happens. I was excited!** (A-2)

> **It was just so amazing!...It's like four World Series all put into one. It's just such an experience....All I know is, it was moving, really moving....That's when I started to cry. I was just so happy....Like soon as he was out--he just popped his head out and opened his eyes and looked at me. It was like that's the first thing (that it feels like) that he saw in the world.** (C-1)

One father who said he gets nauseated at anything medical got so excited by the birth of his son that he forgot to be sick.

> **[The birth was] rather nerve wracking, exciting, scary all in one. I don't know, I am [usually] kind of queasy [but]....I, more or less, just got right in their way and they were wiping him and cleaning him up and I was more or less, 'Who cares!' [laughing]** (E-1)

Not all of the fathers, however, found the birth pleasantly exciting. Three fathers described fear. One father, who had no advance warning of the anomalies, experienced a feeling of fear during the birth as he puzzled over what had happened to his child.

> **When they brought him out he had a big lump on his back and at first I thought it was like she had a twin or something and something happened....The first reaction is like, 'WHAT is happening?' And I got scared there for awhile.** (D-1)

Two of the fathers who had been presented worst case scenarios prenatally also described fear because of what they saw.

> **When [he] was born we had been given some information, but I guess nothing really sets your expectations for what you're actually going to see....I think what really scared me was the fact that it seemed worse than I had been led to perhaps expect. But it kind of brought to mind worst case of all the things we had heard about, and the fact that he's probably more on the extreme poor side than the good side.** (B-1)

> **When he was born he was really bloated. He was all swollen up and they had trouble getting him to breathe at the beginning, so I felt really scared for him.** (F-1)

Immediate Connection

One father described immediately trying to relate to his baby.

> **As soon as he was born--I was right in his face....Hi, I'm Dad!'** (E-1)

Two fathers expressed the uncanny feeling that their baby knew them, and that there was already a bond present when the baby was born.

> **Just in the way he was looking at me...[it was] like he felt secure.** (F-1)

> **I figured he knew [me] right away because of my voice--that he heard my voice through the whole pregnancy while he's in there and I'm talking to her and rubbing her belly and stuff like that....It was weird though, really weird....he had some reactions to my voice--he knew it was me...a very smart son!** [smiling] (C-1)

Delayed Connection

Not all of the fathers experienced a sense of immediate connection with the baby. Some were delayed in their efforts to relate to the baby by emotional reactions or physical separation from their baby. Most of the men described a time of emotional adjustment after the birth which resulted in a sense of unreality of the situation.

> **Like it kind of shook you up for the first hour after it happened. You're still in cloud nine wondering, 'Wow, was that really what I think it was?' After it's over you're still asking yourself. I had just seen a childbirth!** (C-1)

Some were delayed from initial connecting with the baby because of feelings of fear. All three of the men who had described anxiety associated with the birth described feelings of fear which seemed to leave no capacity for other emotions. One father recalled initially being caught up in worries about many potential dangers for his twins and then later (when he got to hold the babies) feeling "proud" and "happy" about both of them.

One father (whose son's anomalies were totally unexpected) described fear and shock which seemed to momentarily paralyse him. But his story indicates that after the fear subsided he made a decision committing himself to be there for this child--no matter what happened.

> **I was just scared there for a little bit, but after that, no--I'd be with him no matter what happened.** (D-1)

It is interesting to note that this father seemed to react very much like the fathers who had received the prenatal diagnosis, although in a contracted time span. He seems to have combatted the helpless feelings engendered by the shock of seeing the defects by deciding what helpful role he should play in his son's care--being there with him to watch over and protect and comfort him.

> **The shock only lasted for maybe 5 or 7 minutes, but...I know what I have to do, just do it. So...I just stayed right by him.** (D-1)

Another father spoke poignantly about not being able to "feel" for awhile after the birth and then being overcome by emotion because of his baby's pain--an experience which resulted in holding back development of further emotional attachment due to fear.

> **They took him out right away [after the birth], so we didn't really get a chance to see him. They took him out and got him ready for the transportation to the [other hospital], so I stayed with his mom for a little while and she told me to go check on him....I stayed with him while they**

> **got ready to go, and then that was the first time I really felt because he was in pain and it was almost like I felt that pain because he was a part of me. So I kind of broke down, but I just held him while they were waiting to transport him and then they transported him to the [other hospital] where he got his operation the next day....I guess I felt really scared and I was kind of scared to get attached to him right then.** (F-1)

Most of the fathers experienced physical separation from their babies shortly after the birth. None of the fathers was allowed to hold his child right after the birth, because all of the babies were taken aside for medical treatments. Some babies were quickly prepared for transfer to another hospital without allowing opportunity for the parents to hold and talk to them. The tone expressed by the fathers was predominantly one of deep disappointment about the separation at a time when they so much wanted to have contact with their infants.

> [Before he was transferred to the other hospital] **he was in the incubator. I got to put my hand in there and stuff, but I never got to actually pick him up.** (A-1)

> **So we went up to ICU right away** [after the birth] **and they were asking me questions and what I did was I stood back and just watched [until they transferred him to the other hospital].** (D-1)

> [After he was born] **they just throw him 'Bang!' into a cart, wheel him into ICU right away. [It] was like, 'Oh, my God!' You think, ...'What's going on here?'...Oh, I got to touch him, but I didn't get to hold him like you see in all the movies and everything--as soon as he's born they put him in your hands. To not do that, I kind of felt left out.** (C-1)

> **It could have been like 45 minutes or an hour [until I got to hold him], but it seemed like a long, long time....You watch these films that they show you in childbirth classes and they say how critical it is that the mother and child bond...within the first 15 minutes and so on, and they never suggest that the father should [laughing].** (B-1)

Being There as a Protector

One of the strongest early emotions expressed by these fathers during their time of beginning to relate was a desire to protect their baby. One father attributed it to biological instinct. All of the fathers described a strong desire as well as a sense of responsibility to protect their babies both physically and mentally.

> **I've never really felt that protective over anything, except for maybe when I was a little kid...my dog or our horses or something....It's even greater than that.** (E-1)

> **You could say I was like a big eagle sitting up there watching, 'Come near my nest, you hurt my nest, and I'm coming for you.'...It's just you have to [protect]. Well, you don't have to--it just comes natural. It's an instinct.'** (D-1)

The men identified this protectiveness as an important part of "being there" in the way they desired to relate to their child.

> **[Being there means] you always look out for your children.** (A-2)

> **[To be there is] to make sure he's okay, to make sure he doesn't catch a cold,...to make sure he can pull through this first year.** (F-2)

Protecting also decreased their sense of helplessness--it made watching and staying beside the baby important as part of their helpful role as a father. The actions seemed to imply that they were capable of doing something to prevent mistakes or wrong decisions from being made in the hospital.

> **He was transferred [to the other hospital]....I pretty much stayed with him because I've heard too many stories of babies getting lost and...getting tagged wrong around the wrist.** (E-1)

> **I step in and say, 'Look, I'm the FATHER here--I think I know what's best for the kid!...Don't try to over push your boundaries, you know, like I'm a very protective person!' And, we kind of let the doctors know that....They know that we got it down, and know, too, that we're the parents, not them.** (C-2)

Two of the fathers, however, emphasized that they do not feel any more protective of this baby than of their other children. One of these two fathers further explained that overprotection could be detrimental to the development of independence for his son, but both described protective actions on their baby's behalf.

Factors Influencing Protecting

The fathers wanted to be there to protect their babies from any pain or harm, but their childrens' anomalies required treatments--many of which caused pain or presented the possibility of harm. When the fathers could not protect their babies from painful or dangerous procedures they felt somewhat helpless. When the treatments were necessary, they could not do anything about the situation, and thus could not even actively combat their own helplessness by performing a helpful role. This resulted in considerable distress for the fathers. However, consideration of the benefits of the treatments for their child and the competence and experience of the health care workers helped the fathers to cope with the helplessness they felt when they could not protect their babies. These cognitive coping strategies usually allowed the fathers to hold themselves back from preventing the treatments, but an emotional price was paid by the fathers--anger was felt, but not acted upon.

> **It really [#^&@#] me off...they were giving him needles. They were poking him all over the place. They were treating him like a piece of meat, but they did save him and that was the main thing.** (F-2)
>
> **We were thinking how a wounded mother bear would feel if her cub got taken away--kind of like that's my wounded child and you're telling me we can't hold him, we can't do this, you can only touch him....And we think about it and they're there for him....It's a line that you just had to cross.** (F-1)
>
> **I've realized that everything (like even at the clinic) that they've done, even though I don't like it, it's for his own good, right?** (C-2)

Considering the competence and experience of the health care workers also allowed the men to restrain themselves. Because the treatment role required expertise which they did not have, it was necessary for them to entrust their child to those who did have the necessary expertise.

> **If they would have hurt him or something, yeah, I would have probably stepped in there, but I would have just stood back [otherwise]. They're professionals--that is what they are paid for...so I am actually pretty proud of myself. (D-1)**
>
> **I figured these guys are experienced people. You've got to trust somebody.** (A-1)

This may have led to some exaggeration of the competence of the physicians, or perhaps some of these families truly had outstanding surgeons. At any rate, two of the fathers seemed to take comfort in knowing their child had a great physician.

> **His surgeon is one of the best surgeons in North America, so there's no real problems there.** (F-1)

> **[The doctors] did a phenomenal job. [Our surgeon] brought in a plastic surgeon to close up the back and I guess the job that's been done there has just set a new standard as to how these things should look.** (B-1)

Treatments experienced without the mediating conditions of perceived benefits and trust in the competence of the care givers, however, resulted in protests on the father's part to protect his baby.

> **What they were mainly doing is that they were constantly catheterizing him because they figured that he wouldn't be able to completely pass his urine. And I mean they were doing this like several times a day to the point that they finally caused an infection in his bladder....So then they started to back off and they got it to the point where they said, 'Well, we'll do it just once a week.' And I said, 'What would once a week do?'...I am just curious like on a normal functioning person at any point in time would you not find some degree?' And...they were fully agreeing--on a normal healthy person this [amount] is approximately what we would expect to find.** [so the catheterizations were stopped] (B-1)

> **[The doctors asked] would we mind [having] a student doctor perform surgery? Like why would you ask us, you know, he's not a lab rat! You're not going to let some student, you know, make a mistake and then 'Sorry fellows, we're sorry!' No, I ain't signing these papers and put 'em where...the sun don't shine....We want professionals only on the kid.** (C-2)

Being There as a Comforter

All of the fathers expressed a desire as well as a sense of responsibility to comfort their babies physically and mentally.

> **I mean, [comforting] that's...my role. That's what you are a parent for--to help your kids.** (B-1)

> **The first time when he went [for surgery], I left and went to work and that was terrible....This time I took the day off....You want to be there to comfort him after he just went through that.** (A-2)

One father identified comforting as one of the important ways that he believed a strong relationship is developed with a baby. His description of comforting illustrates the idea of truly being there for the child's need--an action resulting in trust and future reliance for all sorts of situations.

> **When he needs mental comfort....You just pick him up--'Daddy's here.'...'Whatever you need I am going to be here for you.'...Just give me a sign and I'll be there for you.'...You know you're there every day for your kid physically....but it's just the mental part just to try to get it into his head that, you know, he can trust you....I know he can feel it. He knows that I'm his dad. And he knows that I'll do anything for him, and that I don't scare him in any way.** (C-2)

One man even concluded that being there in a comforting role had relayed a message to his son which he believed gave him the will to fight for life.

> **I think just us being there really encourages him....I think that's why he always needs to be close to somebody because during the time when we are all praying for him I think he felt that, and he felt needed...and that's what brought him back into this life....That gave him reason to fight.** (F-2)

Sometimes it was the only action they could do to help.

> **It kind of gets me aggravated the way he gets frustrated because there's nothing I can do to help him.** [I: Make you feel kind of helpless?] **Yeah, I don't know what to do when he's frustrated like that. All I can do is hold onto him--just care for him.** (F-1)

Comforting also provided the fathers with a sense of accomplishing a helpful role and this combatted feelings of helplessness.

> **[At the hospital] I could feel the tension in him. I could feel him being scared....So I stayed beside him, hold his hand, and rub his head and say, 'Everything's going to be fine--I'm here.' And then, they'd go to touch him and he starts to squeak because he's not used to anybody touching his back....So, I'd calm him down and I can give him a hug. I don't know what it is, or how you calm him down, but ....it's unique, it's different,...because he knows you're there....'Where is my dad? As long as my dad is here, I'm okay.'** (D-1)

> **It's really great when they are upset and they are crying...that we can just pick them up....they just snuggle in there [against the chest] and it almost**

> **doesn't matter what's wrong--they just settle right down....It is just a very positive feeling to be able to calm someone down and have them feel so happy that they're with you.** (B-1)

> **He's crying, he wants something, or he's scared, and when he goes in your arms and he calms down and he's comforted, it makes you feel like you're the world to him--like he's been waiting for you for a long time....It's like I'm a millionaire, like I've got everything in the world....It just makes you feel like, 'Ahhh! I did the job.'** (C-1)

Factors Influencing Comforting

The only hindrance to comforting which was described by the fathers was separation from the baby at the time he most needed his parents to comfort him. One father described his concern that his son might feel deserted because his parents could not be there to comfort the baby when he came out of anesthesia .

> **After the surgery and stuff to wake up after he's seen all those doctors and stuff--even before he even seen us....It probably just confused him like 'What's this? Where's mom and dad?', you know? And then when he hears our voice,...it calms him down (C-2)**

At times health care workers were perceived by the fathers as trying to spare the fathers' feelings during painful procedures by not allowing them to be present. However, this caused frustration as fathers considered it their place to be there to comfort their infants at such times. One father described being treated in this manner with his older child's medical testing and resolving not to be kept from being there for this child.

> **I am saying, you got this wrong--that's exactly why I would want to be there. I'm not going to have you take my child off somewhere and do something that's going to be very painful and she doesn't have any of her parents there....My place is to help and comfort my kids, so if they are going to be under a stressful time I expect to be there.** (B-1)

Being There Spending Quality Time With the Baby

All of the fathers stated that time spent interacting with the baby, either in child care activities, in play, or just in getting to know one another, was the most important factor in their relationship development.

> **You've got to spend time--donate time to your family--or else you are not going to have anything.** (A-2)
>
> **My important role [is]...spending as much time as I can and just get to know him.** (D-2)
>
> **Spending time with them mainly--that's the number one thing. There's no sense having kids if you are not going to spend time with them. It is like why did you have them in the first place?** (B-1)

The fathers described getting to know one another as something that takes place over time.

> [Re: getting to know the baby] **I think that you just reach out and do that yourself...as he gets older you start to grow with him and then you become, I don't know, you just become more familiar with each other.** (A-2)

Factors Influencing Spending Quality Time With the Baby

The fathers identified two main hindrances to spending quality time with their babies--the baby's hospitalization and the father's employment commitments. Most of the fathers identified their wives as being most helpful to their experience of spending quality time with the baby.

Hospitalizations. The baby's time in the hospital presented some hindrances to father-infant relationship development. Physical separation and hospital policies interfered at times with relationship development. Nurses both helped and hindered father-infant relationship development while the baby was in the hospital. The fathers described their baby's hospitalization during the first few weeks as hindering relationship development because spending quality time with the baby was difficult and the babies spent more time with the nurses than with their own parents. Most of the babies stayed in the hospital for anywhere from a few days to weeks after the birth as they underwent back operations, shunt placement operations, revisions of shunt placements, and other surgeries or treatments. One of the babies spent all but one week of his first two months of life in the hospital. The fathers expressed some jealousy and some worries that the babies might get more attached to the nurses than to their parents.

> **Like the first four months he was in** [the hospital off and on (for eight admissions)]**....It was like** [the nurses] **were seeing him more than we were. We worked night times and we'd go up there 1:00 o'clock in the morning, is the only time we can get to stay till 3:00 or 4:00, come home, get up, and go to work again. And it was kind of, you know, they're spending**

> **more time with him than we are and so that kind of got us enraged because they're playing with him and doing whatever with him and we don't do nothing.** (C-1)

> **It was pretty difficult to get down there [to the hospital] and actually be able to spend any great length of time with [the twins]....[But] you kind of like them to think when they left the hospital that, 'Yeah, there were all those nurses, but there were those two people who always kept showing up.'** (B-1)

Most of the fathers expressed appreciation that the nurses encouraged them to come whenever their schedules allowed, but sometimes the fathers became angry because they were not allowed to interact with their babies as they wished. Most indicated that they usually did not express their frustration to the health care workers.

> **I could go in there anytime...24 hours a day....I could care for him as much as I want [usually]....[But] I went in there one day and I asked if I could carry my son, but there was a woman doing a checkup on him...and she told me as soon as she was finished. So she was about 10 minutes, and then I went to hold him and she said, 'Well I'm not done yet." She went and sat down instead and I said, 'I'll carry my son!' and I picked my son up and she kind of got [mad] at me, so that kind of aggravated me. I didn't really say nothing about it to anybody there.** (F-1)

Sometimes the fathers felt like outsiders in the hospital setting. They described feeling left out and yet unsure whether they were meeting the expectations of the health care workers in their baby care.

> **We really felt like we didn't want to intrude, but we also felt like we weren't doing enough.** (A-1)

The fathers wanted to do child care activities for their babies while they were in the hospital and identified this as one way to let the baby know that they were there--an action which the father perceived to be helpful in developing the parent-infant relationships.

> **I like going down there and doing those [child care] things. It was nice to spend time with them, because there's no sense being there if all you're going to do is just...be in the same room at the same time. They won't even know that you're there....You wouldn't want to have them sitting there saying, 'Well where did the nurses go and who are these two strangers?' [laughing].** (B-1)

Most of the fathers had positive comments, however, about how the nurses encouraged them to take an active parenting role with their babies.

> **Most of the nurses were pretty good and so they...thought that if the parents were there then the parents, I wouldn't want to say, ran the show, but they would always certainly defer to you....You'd get different opinions, but certainly they would never suggest that you couldn't handle [the babies] or something like that, or that you shouldn't be doing that or whichever. We never had anything like that.** (B-1)

> **They're professionals--they knew what they were doing. It's their job--they're not there to take him away from you, they're just there to give care for him in the meantime when we're not there.** (C-1)

Some of the hospital nurses taught the fathers about baby care and especially about the special types of care the babies needed because they had spina bifida.

> [The nurses taught me] **how to hold him (demonstrated a football hold)....[and] carry him like a monkey would carry his kid up a tree....Yeah, they showed me stuff like that.** (D-1)

> **I had to learn** [from the nurses] **how to catheterize him before I could leave the hospital,...and watch for his back, and...about his head swelling up, you know, what to look for.** (A-1)

Some of the nurses helped the fathers to be more physically and emotionally able to be there for their children in the way the fathers desired to be by showing concern for the father's health and well-being as he stayed for long periods with his baby.

> **Really, really nice, [the nurses] were all nice to me. They asked me a few times if I wanted to go home or they got a place that I could sleep, if I wanted. And I said, 'No, I'm fine where I am.' I sat in the rocking chair by his bed.** (D-1)

> **They fed me snacks or whatever if I was staying there, so...I could care for him as much as I want.** (F-1)

The nurses' evident care and concern for the baby also helped some fathers because it reinforced their ideas of the significance of this baby as a unique individual and helped them to leave the baby knowing that he would be well cared for.

> **My son was number one to me. You know, I think he should be for them, too. It's nice to have somebody else, be there for you, too, just in case.** (D-1)

> **Even the nurses that were assigned to him they were coming to visit on their free time--coming to visit my son....You know, they're not supposed to do that because in that line of work you are not supposed to get attached to your patients and stuff,...because at any time it could be over for that patient.** (F-2)

Some of the strategies that nurses proposed for encouraging parent-child relationship development were rejected by the fathers, especially the idea of leaving a picture of themselves on the baby's bassinet. Most acknowledged having been encouraged to do so, but none acted on this suggestion.

> **We had a little toy that we bought the day that he was down there and we had a couple of toys that we got for him when he was born--not really any pictures, no. I guess we didn't trust this [idea].** (C-1)

But some of the nurses undertook actions which contributed greatly to keeping the parent-infant relationship connection alive when the parents could not be there. The nurses really encouraged one family by giving the parents a special Christmas gift because their two week old baby (who had been hospitalized since birth) could not yet go home at Christmas.

> **[The nurses] gave [my son] a stocking, a couple of stuffed toys, ...and then this was for mom and dad, eh?** (showing a beautiful picture of his son in a red stocking cap which totally hid all of the tubing and paraphernalia attached to the baby) **This really made our day. We went there on Christmas day and this is what they gave us....That was...a very emotional day...**[sounded choked up with emotion]...**because we had no pictures. You could go in there and do it, but he had tubes and stuff all over his head and that, so you don't really want pictures like that.** (A-1)

Employment. The mens' job responsibilities sometimes hindered the father-infant relationship development. Spending the amount and quality of time with the baby that they desired for relationship development required adjustments for some fathers. Aside from hospitalization, work responsibilities were the most commonly identified hindrances to spending time with the baby. Most of these fathers made some modifications in their work situations. One father informed me that he will be changing jobs soon in order to have a more manageable and predictable schedule and more time with his family. Another changed his job early in the child's life in order to be in town more so he could have more time with his baby. Others did what they could within their present job constraints to either increase or improve their time with the baby.

> **I've got the type of job that from time to time you either have to be out of town or I have to spend a lot of time at the office....So I've had a couple of nights where I've had to work to midnight or later....Even after that then you're tired for the next few days, so then it's harder to spend quality time with them because you're just not as 'up' because you're tired....So it is pretty difficult right now to be spending a lot of time away from work when I'd like to, but I do what I can....I have changed the way that I work....Unfortunately there has to be a balance between the two--we definitely need my job [laughing].** (B-1)

> **The past few months they're really overworking me and stuff like that....I've spent time, but not the long quality time [I] would like to because I'm working 21 day/25 day months...But I've talked to the boss already, and I've slowed it down. Like I told him, 'My family comes first.'** (C-1)

> **I get - what is it a week out of month [at home]....I go away for two weeks and I'm home for a week....It's getting harder all the time--harder to leave [for oil rig work out of town]. The last couple of times I go to leave and I'd be standing at the door just not wanting to go....He's the big part of the reason.** (E-1) [It is interesting to note that this father changed jobs shortly after this interview so he could work in town and have more time with his baby.]

Spousal support. Wives helped the father-infant relationship development. All of the men, except one separated father who was fighting a battle for access to his child, said that their wives helped them the most in their efforts to spend quality time with the baby. Wives helped by arranging time for the father to be with the baby.

> **I would say probably [she was most helpful] just making sure that I would get to spend time with them rather than just saying, 'Well look I will take care of the kids and you go off and you do this and this, or you are tired take a nap or something, or why don't you just get the basement done, or whichever...making sure that I have time to be with the boys.** (B-1)

Wives helped by keeping the father-infant connection active during separations. The mothers did this by telling the father about interesting developments which had occurred while he was gone and by talking about "Daddy" to the baby.

> **She certainly sees things that I miss because she spends more time with them, so then she makes a point of passing those along.** (B-1)
>
> **She always tells me when he does something new. 'Oh you should have been here to see this!'** [chuckling] (A-1)
>
> **She always mentions my name towards him when I'm not around...and calls him 'Daddy's twin' and all kinds of stuff.** (F-1)

The wives assisted the fathers to become more comfortable spending time with the baby. They accomplished this by helping the father to get to know the baby and to acquire competence and confidence in baby care and by personally performing the activities which the father would find frustrating or unmanageable.

> **[My wife helped me to get to know the baby] helping with the little hints like this is his attitude when he's this--hungry. And he's crying like this, his 'phoney cry.' [She] helps me with a lot of things like that.** (E-1)
>
> **She showed me the positions--how to hold a child, how to feed him, the temperatures of the fluids, how to change...and the most important thing was how to bath....Yeah, [girls learn that] when they're playing dolls and stuff. Men just don't learn because we're not girls....She's helped me along a lot....I'm still learning....She's trying to help me learn.** (C-1)
>
> **[My wife] bails me out when he gets sick and stuff. I can't deal with that--I just don't have the stomach for that, so she does that. She gets sort of the raw end of the stick....I wish I could and I try to help sometimes, but I do and I have to leave....I can't do it--what can I do, right? If I had to do it I guess I'd learn pretty quick to grow onto it, you know. Sure, but I'd rather not, thanks!** [laughing] (A-2)
>
> **I don't change his diapers because I don't have the stomach for it....She does something called catheterization....I don't do that because it hurts me to see that happening to him....I don't think I'd be able to handle it watching that or doing it on my own.** (F-1)

Summary

In summary, the baby's birth provided the opportunity to begin to get to know the baby and be known by him. For most of the fathers, initial connecting with the baby was delayed by emotional turmoil and physical separation from the baby. The fathers desired to be there to protect, comfort, and spend quality time with the baby--all of which they considered to be important for developing a strong relationship. Prolonged and/or frequent hospitalizations presented hindrances to performing these father roles. Being unable to protect their baby from pain and danger resulted in some feelings of helplessness with which the fathers coped by considering the benefit to the child and the competence of the health care workers. When benefit and/or competence were in question, the fathers protested until the situation was changed. Employment hindered some of the fathers from being able to spend quality time with their infants. Individual fathers considered their work situation and most changed what they could to allow more time with the baby. Wives were described as being most helpful in assisting the fathers to spend quality time with the babies.

In the midst of all these strong emotions and changes, these fathers were trying to be there for the baby in every way they could, in spite of many factors which threatened to keep them away or to make them unable to effectively fulfil their desired roles. The things they learned about their babies during this process, the ways they demonstrated their caring to their babies, and the emotions and struggles they overcame all helped them to become more able to "be there" for their babies in the manner that they wanted to relate. However, raising this baby was still difficult and there were remaining challenges for the fathers to overcome in the process of becoming able to fully and freely be there for their baby--no matter what.

Looking Beyond the Situation

For most of the men the process of looking beyond had begun in the pregnancy as they dreamed of their fantasy child. Most of the dreams they described involved a child who was beyond infancy and at an age when they could do things such as sports activities together. When the prenatal diagnosis disrupted these fantasies, the fathers were uncertain of what to dream that potentially could happen. After the baby was born, even trying to find a helpful role for himself was complicated by the unusual care and treatments required because of the spina bifida. Looking beyond the present and beyond the disability helped them the cope effectively with the stressors of the situation and to develop the relationship.

Looking Beyond the Present

Early development of the relationship was difficult for some of the fathers because the babies seemed delicate, the fathers were learning so many new things about their babies, and there was little feedback from the babies to reassure them that they were doing well.

> **You know, at the start they ate, [had a] diaper change, and slept...but really there's not a lot of interaction. It's really at best a one way street--they may notice that you are doing something.** (B-2)
>
> **As you look at babies, I sort of kind of have a tendency to veer off....they're too delicate.** (A-1) [and later] **Once he starts talking and stuff then you get to see how he actually feels. But it's hard....Sometimes you can tell by the expression, but then there's other times you can't....You'd like to know what he's thinking, but you don't know.** (A-2)

The added challenge of learning how to deal with complicated health problems when there was little feedback from the baby also caused some stress for the fathers. Anxiety about their competence with treatments and knowledge of danger signs required perseverance for the fathers to keep trying until they were confident about the child's care and to do the best they could in the meantime.

> **At first I was kind of nervous because, you know, if he's 'special' or whatever, but he's not really. I don't think he is....It just takes a little bit more to take care of him, but not really--it's just different.** (A-2)

One of the most frightening aspects of care for most of these fathers was the baby's crying, because intense prolonged unremitting crying can be a sign of shunt obstruction leading to dangerous pressures of fluid in the brain. Uncertainty about whether the baby has shunt problems or is crying about something else resulted in agonized questioning and frustration for the fathers. The fathers did not want to take the baby to the hospital needlessly, but the baby couldn't tell the father what hurt.

> **If the kid's screaming that's the first thing I think about. 'Is his shunt's hurting or something?' Because he was doing that there last week, but [he was] teething I guess.** (A-1)
>
> **[The crying] would go on for about an hour and...I just lost it. I said, 'Ok, that's it! I just can't take it no more--he sounds really bad!' Every minute he's whining, like he's really sore, and like it kind of gets to you. It gets inside of you to make you feel bad, so...we took him [to the hospital] right away.** (C-2)

Building Dreams for the Future

Emotional energy required for child care when there was little feedback or reinforcement seemed to be largely sustained by thinking of positive possibilities in the future and keeping their thoughts on the outcomes of their goals. As one father explained it, looking ahead "**keeps one...more focused on the positive aspects of raising the child rather than getting caught up in some of the more near-term problems.**" (B-3) Many references were made to future plans and dreams while the babies were still very young. The men described the games they would play, places they would go with their child, and in some instances acted out both sides of dialogues they expected might occur in the future.

> **[He will be] my fishing partner [laughing]....I like the outdoors very much....Mom will be saying, 'Take him.' She won't even have to say 'Take him.' She'll be going, 'Bye!' We'll be going out the door. 'See you later.'** (E-1)

Consideration of the future, however, was bittersweet--thinking of the future also reminded the fathers that some of the dreams they had cherished for their child would not be fulfilled. Hopelessness about unfulfilled dreams was combatted by building alternate achievable dreams. The fathers whose personal interests involved active sports seemed to have the most challenge with rebuilding their dreams for their child. The uncertainty of the baby's prognosis left some of them with less positive material to form into pleasant new dreams, but dream they did! They began to think of areas in which their child could excel, rather than dwelling on the things he could not do.

> **I'm on baseball teams, for my whole life I've been on and that's been a dream for me--was for my son to be the world's greatest back catcher or second baseman....No matter if he's got it or not--he's going to be swinging that baseball bat....Sure, it turned out I was thinking about his futures and stuff like that, but, you know...if there's one thing he can't do--there's always another that he can do. If he can't play baseball--he can be a computer genius. He can be something better than a sports star.** (C-1)

> **His own path, you know we would like to encourage him. I'm more than positive that we will encourage him to get into sports--hockey. If he wants to be a ballerina or whatever he can try it....Play the drums or the trumpet if he wants....It might be a little nerve wracking,...but if he wants to try it, we'll be more than willing to support him....The way I see him now is something in a lawyer firm or a doctor. He's going to be rather high up in a corporation.** (E-1)

> **His happy-go-lucky attitude has been a real blessing and it's something that I think he's going to need as he grows up...because...there may be some things that other kids can do that he can't do. And, in turn, he...is likely to get good at doing some things that they don't get good at because**

> **he's got more time to do whatever. So it may turn out that he'll be great at playing the flute or something.** (B-2)

Developing a Helpful Role: Preparing for the Future

Looking beyond the present motivated the fathers to do what they could to prepare both themselves and their baby for the future. Learning more about the baby's condition decreased uncertainty about the future.

> **Learning more about what his situation is...helps me....You know, even though I don't look at him negative or anything--just learning more about what he can do and what he can't do just helps me realize what's going to happen in the future.** (C-2)

Even though their babies were very young, all of the fathers expressed concern about adequately preparing their child with the knowledge he would need for the future. After considering their own beliefs about what is important for life, they decided that the most essential knowledge they wanted to relay to their children involved how to know right from wrong, how to be successful even in failure, and how to live well in spite of handicaps.

> **I wanted to have a good relationship--not...my son to go look to [his] friends' fathers for a little bit of guidance from them. I wanted to give my son all I can....He's a bit young, but...the way he is going right now, he'll probably be really mature by the time he hits 5 or 6. He'll know right and wrong really well and I won't have to be there to tell him 'yes or no.'** (C-9)

> **My important role is... [to] show him things...trouble things like--don't do this or watch out for this....You have to show them right from wrong.** (D-2) **I don't want him picking up any bad habits because when he gets older I'll tell him some stories. I'll take him out and show him places, and things, and people, and say, 'See, look, you want to be like that or you want to be like that? You're too smart for that. You're too good for that.'** (D-1)

> **[Being there] means that as they hit their challenges in life and they need somebody to help them understand it [you] help them to think it through to understand right from wrong to understand the implication of what it might mean if they did this versus if they did that.** (B-2)

Most of the fathers considered it important to teach their child the things he needed to know to be successful in life including how to fail successfully. Their desire to help their children become successful seemed to be closely related to their developing love for the child. Several of the men who expressed concern spoke about the importance of teaching the child that he is loved unconditionally, and that he never has to earn his father's love by accomplishments.

> **The most important thing to help your child be really successful is lots of love and lots of guidance.** (C-1)

> **Just show him that...whatever he does wrong is not going to snap your nerves first try or anything like that. Show him that... [you] love him no matter what he does...Like...our T.V. converter he took it and threw it on the floor and smashed it....'Ok, next time don't do that.'** (C-2)

> **Teach them how to make friends...just making sure that they understand about life. I guess passing on all of the things that I have learned...so that hopefully they come out even smarter and better....You've got to teach them sports, and teach them about art and music and everything else that makes up life....[And being there is] building up their self-esteem, their self confidence, things like that, so that when they are young and they are trying things and they fail, making them understand that failure, in itself, is nothing bad and it's just an opportunity to learn....At some point he's going to realize that his life is just not quite the same as other peoples' lives and that he has these other challenges and the result of that might be is that he might...begin to worry that 'Mom and Dad might not love me as much because I can't accomplish the things that other kids are doing.'...I felt it was important to make sure that he most clearly understood that he was loved and wanted and needed and that we were going to do our best for him as we will for [his brother and sister].** (B-2)

Preparing their child to live with his handicaps also involved teaching the things he needed to know to live a respectful and respectable life in spite of his handicaps.

> **The Bible is very important [to teach]....I want him to have respect. I want him to learn the 'thank yous'--the good words....I don't want him to...take things for granted...I want him to learn a few little things--responsibility, how to handle things....It might take ten years, but as I am teaching him and being with him, it will help him out.** (D-1)

> **The way I define smart is--somebody asks you a question, you have an answer for it,...respect your elders, good work habits..., being there for other people that are there for you--just not like a school smart, just an overall life sense smart....Sure I will guide him in a few ways, and if he doesn't like it he'll tell me, 'Dad I don't want to do it. I can't do it', (but**

> that's one word I don't want to hear from [my son] is 'I can't, I can't')....I don't want him to feel that he is [handicapped]...because he will get that in the back of his head for the rest of his life, saying, 'Oh, man, I'm a special kid--I can't really do that and this and that.'...I'm going to let him do everything he wants and what he can't do, 'Fine.' If I can't help you with it, and we can't do it together we'll just push it on and move on to something else together.' (C-1)

> Respect--I'd like them (my kids) to know respect. Also, I'd like them...to stay in school....In today's world...you need an education. You can't get nowhere without it....I just want to warn him that...there will be people out there who will make fun of him, just not to let it get to his head (all the %^^&! out there),...just to be proud of who he is, just enjoy life one day at a time,...and to take it as it comes. (F-1)

Summary

Looking beyond the present seemed to help these fathers to be there for their babies in the manner they desired. This seemed to give them reinforcement for their baby care activities during the early days when the work required of them seemed to outweigh immediate relationship rewards. Emotional energy seemed to be maintained by dreaming of a positive future. Adjustment to the idea of handicaps was fostered for some by rebuilding new dreams which were more achievable with this child--an action which combatted hopelessness. Thinking of the future motivated the fathers to further expand their helpful role in the life of their child to include preparing the child for a productive and satisfying future. This role required the men to prepare themselves by learning more about their baby's condition and future prospects. They considered their beliefs about what is important in life and decided that they wanted to teach their children about right and wrong, success and successful failure, and how to live well in spite of handicaps.

Looking Beyond the Disability

Because the fathers were receiving so much bad news and the future was so uncertain, hopelessness became a threat which increased if they focused on the negative aspects of the situation. Looking beyond the disability helped the fathers to have hope that there could be a positive future for their babies and for themselves. The positive feelings which hope engendered helped the father-infant relationship development.

Combatting Hopelessness: Building and Maintaining Hope

They combatted hopelessness by the use of two major strategies which built and maintained hope--replacing negative ideas and maintaining an acceptable level of uncertainty. Most of the fathers spoke about the importance of hope in their lives and described experiencing struggles at times to remain hopeful when so much of the news was bad.

> **That was the most challenging part of the whole thing was to constantly get all of this very negative news....Without hope, the stress is just going to take off like a rocket because you don't actually know if you can really deal with [it].** (B-1)

One of the fathers indicated that his hope needed to be built back up periodically especially around clinic times.

> [Re:Building up hope] **It's usually every time we go to the clinic....[It's] kind of a reminding scene, doctors sticking needles into him....He starts crying and you know you can't really do anything about it because it's his time to get checked out. And that's why I don't really like that. This is what makes you start thinking, right?** (C-2)

Replacing negative ideas with positive ones. Having more positive conceptual material to work with helped to build and maintain hope. Replacing the negative ideas took effort on the father's part. Some used combat terms to describe dealing with the negative ideas such as "kicking out," "beating out," "blocking out," or "pushing back" the negative concepts and replacing these with positive ones. The comments indicated that the process of replacing negative ideas was a recurring action and part of what one father described as the "low points" of the experience of being a father to this child.

> **I always think positive....It** [the possibility of his son's death] **has come across my mind, but I try to block it out right away, trying to think about something else.** (A-2)

> **You think of the bleak, you think of the worst...and then the positive starts kicking the negative out of there, you know, 'Come on, get it out, get it out, get it out!'...The low points [are] just beating that out of the brain....I don't really think about, you know, his condition.** (C-2)

Negative ideas were replaced using three main strategies: looking for normalness, looking for positive signs, and looking for possibilities of a positive future. Looking beyond the disability to see the normalness of the baby seemed to be very important for these fathers.

> **Mentally, it's tough thinking that your child is growing up with spina bifida, but like I said, you fight it, you push it back and you think he's just a regular kid, which he is--just a regular kid. And that's about the only thing that you think of on and off.** (C-1)

When asked to describe their baby, most of the fathers described very little about actual physical appearance even when asked probing questions about physical features. They tended to emphasize that their babies looked and acted "**normal**," "**healthy**," or "**strong**." Some fathers described their baby's actual appearance more thoroughly during the second interview, which might indicate that looking for normalness was a more important action earlier in the relationship before the fathers had learned other strategies for looking beyond the disability.

> **Very normal--other than having two casts on his feet he's very normal.** (E-1)
>
> **He looks very much like a normal, everyday baby....He's a big bustling baby boy....He has blue eyes, nice deep blue eyes.** (B-2)
>
> **Gorgeous! And his personality--he's just getting really smart....He's healthy and he's a big, fat boy.** (C-2)
>
> **He's cute. I don't know--he looks healthy and everything....You really can't tell that he has a problem.** (A-1) [and later] **He's got brown eyes...He's cute as a button!** (A-2)
>
> **He's really strong. He's very loving--just, overall a good kid.** (F-1) [and later] **It just makes me feel good, you know, just to look at him--he's really handsome.** (F-2)

Seeing positive signs of progress in their babies' development really seemed to promote hope for these men that maybe the future would be good. It was evident from their many comments that these fathers actively looked for positive signs and tried to think positively of their own actions and their baby's actions.

> There's so many positives that happen right now...moving his legs and coming at you...even though he's crawling backwards he's still crawling right. (C-2)

> The positive thing was that I would see him moving his legs from the hips. But you know when they're that small you aren't really sure, but you could see him moving his legs, and then I just felt a thousand percent better because I knew that at least worst case wasn't the case at that point. (B-1) I would say there's been a lot of positive information that has come in....It has just been solid progress--the lack of having to catheterize him, his bowels seem to be getting better, and so on. (B-2)

> [What keeps my hopes high is] just seeing him growing and being alert and he had his one year check up from all his doctors and they said 'For him having spina bifida, he's very alert, he's got no symptoms whatsoever of (they talked all this technology, I can't even remember) like crossing eyes and swelling forehead and all this other stuff.' (E-2)

> For the high points for me it would be...the progress that he's showing, you know, his capabilities...they're kind of surprising the doctors, too. (C-2)

> Everything I do, I try to see it as a positive; and everything he does, I try to see it as a positive. (C-2)

Looking for possibilities of a positive future was another strategy used to replace negative ideas. The men especially appreciated finding out about people born with spina bifida who had done well because this built hope that their own baby's future also might be positive.

> [A friend's] son plays soccer and his next door neighbor is a coach for soccer and they had a kid on there that had spina bifida. Yeah, he said he was one of the most talented kids that you know. (A-1)

> I found that every time we told somebody, everyone had a positive story to come back with....We did have some people say that there's people that have had shunts and they're doctors and lawyers, that people had been born with this and they have gone on...one is supposed to be an NHL "Wayne Gretzky." [referring to a famous Canadian hockey player]...[My sister] said, 'Well, you know, I teach a child who's got spina bifida.' This child when he was born was numb from the waist down...and he was like that for the first three months. And then his mother really started to work with him in a physiotherapy concept type of thing, and he now goes out

> **[wearing his orthoses] and plays tee ball and everything else just like any other kid.** (B-1)

> **We seen this little black kid [at the Spina Bifida Clinic] and he's got spina bifida--and he runs around like a terror. He's darting around.** (C-1)

The men looked for abilities in their children which seemed to bode well for the future. Little actions on the baby's part could stimulate excitement for the father.

> **He's going to be into computers....He's very much (I think) into technology....He's right into it now....He can pick the phone up and he...pushes the numbers and...like he'll see us pushing the [television remote control] changing the channel. He'll see them buttons and he'll change the channel and watch TV and change the channel.** (E-2)

The men also looked for positive personality traits and strengths in their children which could influence their future. All of them characterized their children with terms such as "**strong**," "**a fighter**," or "**a survivor**." Several of them described their child's temperament as "**happy**," or "**easy going**." Others described traits which they considered to be helpful for the child's situation.

> **He's strong, he's really strong. He came face to face with death twice** [the father sounded choked up with emotion] **and he won both times.** (F-2)

> **I think he's going to be a go getter. It's just going to take a bit of influence to get him going.** (A-1)

> **[He] seems to have more gumption, so to speak [than his twin]. He just seems to have more drive to him, at least at this point, and that's good because he will probably need that. But he seems to have a personality that may suit the circumstance that he's in....He seems to have the type of personality that would not get discouraged easily....[My son] tends to sit back--I could see him being a real thinker and somebody who kind of takes it all in first and then says, 'Ok. Here's what we should do' or whatever.** (B-2)

Maintaining an acceptable level of uncertainty. Having some uncertainty helped to build and maintain hope. Not all negative aspects could readily be replaced by positive ones--much bad news and uncertainty remained after the positives were considered. The fathers coped with remaining uncertainty by using strategies which tended to maintain some uncertainty. If one does not know what the future holds, then present negative situations seem less threatening because there is still the possibility of great improvement in the future. Many comments reflected a "**wait and see,**" "**it just hasn't happened yet,**" or "**time will tell**" attitude.

> **Got to wait...to find out what extent [of disability] he actually has....I think a lot of people think it's going to be a lot worse than it actually is....He's so young--time will tell.** (A-1)
>
> **To date, he hasn't moved his toes and he hasn't moved his foot at his ankle. But he seems to have feeling all throughout his foot and that's supposed to be a very positive thing because they say, typically speaking, the motor nerves operate before the sensory nerves. So the fact that his sensory nerves are there gives some degree of hope--it just hasn't happened yet. And it may not, but all you can do is hope and just keep trying. Every time that I get, I play with his feet.** (B-1) **And, you know, it's really just a question now of how far he's going to end up going.** (B-2)

Another form of maintaining hope through allowing an acceptable level of uncertainty involved choosing not to worry today about tomorrow's concerns. This made the present stressors much more manageable and achievements of smaller goals more evident. This strategy was reflected in frequent comments about taking things "day by day" or "one day at a time."

> **Things will come up day by day and you learn day by day because I'm a new father, right? I haven't had a child and I'm learning as I'm going along.** (C-1)
>
> **I would just deal with it** [my son's death, if it occurred] **because I'm a day to day person and I would deal with it as it happened. I mean, you don't want it to happen, right, but what are you going to do?** (A-2)
>
> **I didn't think much of it [possible need for a shunt]. Just let's take one day at a time and hopefully not. But if it happens, lets hurry up and get him to a doctor and see what they can do....Just take it one day at a time and enjoy your baby the way he is, that's all you can do.** (E-1)

Father C seemed to imply that it may not be possible to always maintain a day by day outlook, but that being the father of a child with spina bifida is much more manageable "**if you can.**"

> **Suggestions [for other fathers of children with spina bifida] would be take it in stride, learn as much as you can about the situation, what the word means, and take it one day at a time, if you can. Don't try taking**

> **everything in one big bite and one big jump because you will get shocked if you jump too far or bite too far.** (C-1)

Factors Influencing Building and Maintaining Hope

Worst case scenarios. Most of the fathers identified the worst case scenarios presented by their physicians as the main hindrance to developing and maintaining hope because the news was often so negative.

> **It's like doctors are negative even though they are supposed to be trying to help you to be positive.** (C-2)

According to the fathers, one of the main reasons that the news from the physicians was so negative was that the physicians tended to err on the side of presenting the more severe prognoses in order to protect themselves.

> **They were presenting a fairly bleak picture, I think because they wanted to have us set for worst case and if it turned out better than that no one was going to be upset with them. But if they said, 'It could be this or this, but we will take a mid road spot,' and if it turns out worse, then [the parents] might come back and say, 'You didn't tell us that it was going to be this bad.'** (B-1)

Physicians also were perceived as presenting worst case scenarios in order to adequately prepare the fathers in case the worst happened. One father thought that it was a good idea to tell fathers the most negative possibilities, but another questioned the value of knowing the worst given the long waiting time of uncertainty.

> **What [the doctors] do is they prepare you for the worst....I thought it was a really good plan the way they did that.** (A-1)

> **They're just trying to prepare you so that you don't have to deal with the shock later if it's worse than that. If it is better than there is no shock to deal with--just happiness. But I don't know if that is the best [way] overall to leave somebody for several months.** (B-1)

Others found that this left them frustrated and with little hope.

> **Doctors can be funny that way sometimes. It gets frustrating because they figure he's the worst case scenario and they're going by the stats., the books, or whatever they go [by].** (E-1)

> **Worst case--well, like a lot of them were saying that 'if he has an L3 lesion he is not going to have bladder control'--I mean it's that simple. It is like night and day - if, therefore, then. It is Boolean logic level thinking, rather than saying let's observe what is going on....The picture that they presented did not have much hope.** (B-1)

However, if the goal was maximum preparation the physicians' strategies did not work, even for Father A, who had considered this the best course. He and another father were not sure how to prepare because they were left with uncertainty as to whether the worst was yet to come.

> **It's a really weird feeling. It's like, you get all this stuff explained to you. Well, should this be happening? But it's not happening....They say things are going to [happen like] this, but you don't see it. And then...they're telling you that they are just little babies, eh? So I keep telling my wife and myself that when they get older that's when we are going to experience all this stuff that we got told.** (A-1)

> **The doctors were always very cautious....and they were kind of saying 'Well...it's likely that he might get worse. Even if he gets better, probably it will be a temporary thing,' and so I was always waiting for the bottom to fall out.** (B-2)

One father (speaking from personal experience) expressed the fear that worst case scenarios could convince fathers to give up.

> **Some fathers might get the wrong idea if they say, 'Oh, it's a bad case' and, you know, it's almost like telling them 'You should give up.'...That's how I felt, too, when he went in the hospital a couple of months ago....It felt like they were telling us we should almost give up.** (F-2)

Some of the fathers even doubted the physicians' prognoses thereafter because they concluded that the physicians had either been incorrect in their earlier predictions or must be minimizing any good news in order to avoid overly hopeful expectations.

> **I just shrug my shoulders and just take in what they say and carry on because...my wife and I know what [our son] is like already. Like even [my wife] said, 'Them doctors they don't know what they're talking about--they don't know [our son].'...You've got to see him, you've got to live with him to see.** (E-1)

> **While we were being told that [later bad prognosis] I think we either just didn't accept it or want to accept it or whichever. We just took it for what it was, which was a highly cautious statement from doctors not wanting to set expectations beyond what they might be.** (B-2)

Refusal to accept the physicians' judgement of the severity of the problem could have been very dangerous in one of the cases because the father refused shunt surgery deemed necessary by the physicians. Time will tell whether this refusal has caused any permanent damage for the baby.

> **What they wanted to do was put a shunt into him and I said that he was not strong enough for one thing and that he was too young. I asked them if they would wait and they said, 'Sure, and we will give it four months and then we will put a shunt into him.' When the four months came around, they still insisted on putting the shunt in there and I said, 'No, let's just wait. He's a strong kid and I'm pretty sure he can work this out.'** (D-1)

The fathers were especially grateful to the physicians who had described a range of possibilities and had admitted uncertainty about the prognosis prenatally. This allowed the fathers to maintain some hope--that perhaps the worst case would not occur this time--while preparing for the worst, in case it did happen.

> **Mostly [the doctor] gave us all these different possibilities that could happen, the good and the bad, all the other things--he was brief, however....He didn't promise me, but I assumed from the way he looked at me and from the way he told me that he would help us, and it gave me a really good sense of hope.** (F-1)

One father, who had experienced only the worst case scenario method of relaying the prenatal diagnosis, suggested that knowing a range of prognoses would have been more conducive to hope and adequate preparation for him.

> **I think the number one thing I would change would be [gaining] more information and [talking] to more people about what the range of the impact could be....You could almost have a scale that went down and said...here is the lesion point, and here is the typical impact, so you could almost look at that and say, 'I've got a sense of what we are likely to deal with,' and then something that went up from there, 'That's the possible circumstance.' So as your child grows up, if you were in this group, you probably are going to have to do the following things. If it's worse than that, you'll do these, and if it is less than that, you don't really have a lot to worry about....Set the expectation properly, but don't cancel all hope!** (B-1)

Resources. The fathers described two resources that helped them to build and maintain hope: adequate and current information and religious beliefs and prayer. Four of the fathers expressed much appreciation for the booklets and pamphlets published by the Spina Bifida Association which they had received. All of them had positive comments about their preparation and treatment at Spina Bifida Clinics. However, the fathers who knew about the anomaly prenatally expressed a wish that families of babies with spina bifida be referred to the Spina Bifida Clinics earlier. None of them had been referred to the Clinic until some time after the baby was born--after spending months wondering about the diagnosis and searching for information that was easily available in the Clinics. They described other health care workers, aside from the Spina Bifida Clinic staff, as often relaying inadequate or outdated information about spina bifida. Outdated information tended to be quite negative and to stimulate feelings of hopelessness in the fathers, whereas information about new advances in spina bifida treatments tended to build hope.

> **[My son] stayed in for the first three weeks [after] he was born. Then we found out on the 4th week about...the [Spina Bifida] Clinic....I think it would be easier on a lot of people if...before they give the people back the results of the ultrasound, maybe they should notify the Clinic. Maybe....get somebody to go visit the family...and tell them how it is....That would probably be easier than what we went through.** (F-1)

> **It is like most things, most people when they are talking about a circumstance they are basing it on previous information, and the advances in this area have been fairly good in the last while, certainly the last twenty years. So, when one looks back and says, 'Well, this is usual,' it meant that--that's usually worst case because it doesn't take into account some of the most recent advances.** (B-1)

Nurses in the neonatal intensive care unit of one of the hospitals were perceived by one father as also lacking information about spina bifida.

> **It was interesting [that] even the nurses in the NICU there really didn't have a lot of information on it. As a matter of fact, several of them were reading through the same book [Introduction to Spina Bifida from the American Spina Bifida Association]....They were reading it to gain information themselves, so, at least that was my impression. I mean, they weren't standing there saying, 'I know nothing about this situation, I will sit down and read this book,' but that certainly seemed to be the way that they were going through the book.** (B-1)

Nurses from the Spina Bifida Clinics, however, were appreciated because of the way they helped the fathers to obtain the needed information.

> **We went through the [Introduction to Spina Bifida from the American Spina Bifida Association] and the Spina Bifida Clinic Nurse highlighted the most important, most common questions....You know we went through that all at the [Clinic]...The people are great [there].** (A-1)

The nurses did not have to know all of the answers in order to help the fathers. Honesty about what they did not know was appreciated.

> **[The nurses] were right there all the time and when we asked them questions they answered them the best they could...but they weren't lying to us, though. Like when I asked if he was going to live they said they really don't know.** (F-2)

Adequate information helped the fathers to look beyond the disability and to realize that there are tasks and treatments that can be done to help, so it is not a hopeless situation.

> **Certainly with modern medical science and a lot of hope and a lot of work, most of it seems to be something that gets better.** (B-2)

Adequate information also helped increase the fathers' self-confidence because it gave them hope of having a helpful role in this child's life and helped them to see the situation as a challenge rather than as a tragedy.

> **You learn to cope with it after all the information they give you....You know it's something you can't overlook, but it's something you can help him together to get by.** (C-1)

> **Certainly having a child with a disability is going to offer a greater challenge....**[I see this as] **a positive challenge. This is an opportunity to show my capabilities.** (B-1)

Seeing the situation as a challenge, rather than as a tragedy, incidentally, seemed to encourage humor in the fathers. When they spoke in terms of challenges they often joked about difficulties they encountered facing the challenges related to raising this child. It was acceptable to laugh about the bumbling way they felt at times with child care and treatments because it was a challenging situation which was not expected to be easily overcome.

All, except one of the men, commented about their religious beliefs or prayer in connection with hope. One man felt that God had intervened to change the situation positively when he was very depressed.

> **I guess the Lord above seen that we were so depressed. He must have gave us a zap and said, 'Bang, you're blessed,' you know, because there hasn't been a problem since.** (C-2)

One of the men commented several times about his belief that his child's life reflected both blessings and challenges from God. He expressed a conviction that challenges can be good for spiritual development not only for his son but for himself.

> **I think, in some ways, you know each child comes with his own group of blessings and challenges....And so, regardless of the challenge that he might have, we have the greatest opportunity to allow him to overcome that challenge. Sometimes a bit of a challenge in someone's life is a good thing.** (B-2)

Prayer was mentioned several times by four of the men and it seemed to fulfil multiple functions. Prayer primarily combatted hopelessness and helped some of the fathers to function better as they put their hope in a power greater than themselves.

> **I still go to church and pray...it helps, every bit helps.** (D-1) **It helps me to be more relaxed and more calm that there's a hope there, you know....I say my prayers at night before I go to sleep--I sleep better.** (D-2)

Prayer also helped to combat helplessness because praying was one thing the fathers could always do, even when there was nothing else that they could do to help.

> **You can't control that [possible death of your child]. You just hope and pray.** (A-2)

And some of the men believed that great things had happened in response to their prayers.

> **I think that our prayers were certainly answered in his operation...you can see constant improvement since then.** (B-2)
>
> **Honestly, in my belief, I think that's what brought him out of** [a life threatening illness in which the parents were encouraged to consider disconnecting life support] **was how me and his mother grieved for him and prayed for him.** (F-2)

Summary

In summary, looking beyond the disability helped the fathers to be more emotionally there for their children in spite of continuing uncertainty and an overabundance of bad news. In order to look beyond the disability, the fathers combatted hopelessness by employing strategies which tended to build and maintain hope. Their primary action to combat hopelessness was replacing the negative ideas with positive ones. They actively looked for positive information about their babies, especially normalness and positive signs of progress. They also looked for evidence of the possibility of a positive future based on success stories of others, and positive personality traits, strengths, and abilities of their baby. Maintaining an acceptable level of uncertainty allowed them to hope for the future and to gradually cope with problems.

The main hindrance to building and maintaining hope was presentation of worst case scenarios to prepare the parents. Adequate, current information and religious beliefs and prayer were described as helpful to these fathers in building and maintaining hope. Their comments in the second interview about not wanting their children to grow up feeling handicapped suggests that the subprocess of looking beyond the disability which started for them with the diagnosis of abnormality may continue throughout their childrens' lives.

Together, the actions of looking beyond the present and looking beyond the disability helped the fathers to effectively cope with the frustrations and anxieties they experienced in being there for their children in the manner they desired during the early days of the babies' lives when hopelessness threatened them. However, just ignoring the abnormalities and replacing negative thoughts with positive ones would not have been enough for development of a strong and lasting relationship between the father and his child. Making sense of things is very important for mental health and for the enjoyment of life and relationships.

Finding Meaning in the Relationship

Although the fathers had no answer to the question of why this anomaly had happened in their family, they did find meaning in their relationship with this baby. They found meaning for themselves in the closeness of the relationship, in being recognized as someone special, and in the pleasure of the relationship. Being able to help their baby's development gave them a purpose and a helpful role. They experienced satisfaction when the baby's progress demonstrated that their being there for this child made a difference. The sense of continuity of being able to pass on something of themselves and their most cherished values to someone who hopefully will continue after the father's death was also identified as a source of meaning for two of these fathers.

Finding Meaning in the Closeness

All of the fathers described having a sense of an inseparable bond with the baby. Many expressed identification with the baby--almost as if they were one and the same person.

> **No matter--you can have the worst baby in the hospital--he's your baby, he's you. Just love him the way he is.** (E-1)

Father E connected protective feelings with identification.

> **It's even greater than [protective feelings]...He's me. Yeah, he's me sitting over there.** (E-1)

In some cases, identification with the baby was painful, as Father F so poignantly illustrated when speaking about feeling his baby's pain right after birth. The identification and closeness, however, also resulted in positive feelings deeper than some of the fathers had ever experienced.

> **He is priority on my list above anything. I don't know any words to say, but the love is just too strong, really strong between us.** (C-1)

Finding Meaning in Being Recognized as Someone Special

As the baby gradually became more responsive over the first few weeks, the fathers described pleasure at being recognized as someone special, whose company is enjoyable to the baby. This recognition occurred for most fathers by about the second month of the baby's life. The pleasure resulted in an increased desire to relate to the baby.

> **[The twins have] become more responsive as they've got older, so that makes it easier to play with them** [N.B.: they were born prematurely]**....When they started to beam, like light up...then I really felt they recognized me as someone special...Once that recognition was going both ways...you kind of feel like, 'Yeah, they think of me specially.'** (B-2)

> **He knows I'm there and that shows me that he's really enjoying what we do together....With my voice and the things that I say to [him]...he knows it's me right away, and he's just up and at it and wants to...'Let's go with Daddy!'--crying if I don't pick him up and stuff like that.** (C-2)

> **It gives you a reason to live....Like, sure, there are times when you know you're single, you're going through a depressing day like, 'What am I, I'm not important no more,'...but when you have a baby you think, 'Well, this guy looks up to you--like he already shows that he looks up to you.'** (C-1)

> **It makes you feel good when you reach out for him and he wants to grab and come to you.** (A-2)

> **He sees me and it's hands out and he's just getting so excited....[laughing] Ah, it's just a thrill!** (E-1)

Recognition of the father as someone special was also evident to the fathers because of their baby's exclusive behavior and this resulted in good feelings about the relationship.

> [An evidence of relationship with me is that] **he actually plays strange, eh....to other people.** (A-2)

> **He wouldn't come to you and just be happy...He might scream and cry and look at me and Mom.** [I: Asking permission?]**...[laughing] Yeah, that's pretty much what he does.** (E-1)

> [I know we have a relationship] **just by the way he looks at me. He knows when my presence is absent. I know that because his Mom tells me....He's miserable. He doesn't sleep.** (F-1) **He's always calling for me....When I'm sitting beside him he'll reach out and caress my face.** (F-2)

> **You begin to feel good that they don't want to be with so and so, but they do want to be with you.** (B-1)

Recognition that a relationship existed between the fathers and their babies seemed to involve seeing evidence that the babies "knew them," "recognized them," or "knew [they] were there." Absence of that recognition was acknowledged by one father as a possible hindrance for relationship development.

> **You would be a lot more apprehensive if you have a child who mentally didn't seem to be able to deal with things and, therefore, you weren't even sure if they knew that you were there or not...that would be a lot more difficult.** (B-2)

The only father who did not acknowledge that a father-infant relationship existed by the second month seemed to be waiting for verbal affirmation from the baby. He seemed unsure of whether recognition by his baby was evidence of a relationship. Although he acknowledged early emotional responses of the baby, he wanted actually to be told by his son that he was loved.

> **I guess if you go by emotional, yeah, [there was a relationship early], but...where you really notice it the most is when they start talking....It's always nicer when you can hear somebody actually tell you, right?** (A-2)

Finding Meaning in the Pleasure of the Relationship

All of the fathers described the pleasure they derived from their relationship with their baby.

> **I would say that certainly the interaction...They, you know, do something and then you see the positive change. It always makes me feel good.** (B-2)

> **There's nothing--no words that can explain the joyful feeling of having a kid, and having [my son] is like a whole new world and a new meaning to living....Since he's been here there has been fun and jokes and laughs....Since he's been born it has been like a party.** (C-1)

Even the father of the most seriously affected baby described pleasure relating to his son.

> **It's been an experience but it's been a pleasure. I don't know what I would do without him.** (F-2)

Their baby's smiles, laughs, chuckles, and demonstrations of love thrilled each father and encouraged him to interact more and more with his infant.

> **The nicest thing about being a father is waking up every day and hearing your kid crying and wanting attention and you go over there and give him your attention and he is all smiles and you can see that he has a love for you.** (C-1)

> **Oh, his laughs!...It's a laugh that you've never heard before....It sounds like it's straight out of the bottom of the gut and when anybody...hears that laugh, they just start to laugh because it's funny.** (C-2)

> **It's just great to be with little kids that just look up to you and they just love you and you can't help but love them back...They are always laughing and**

> **kidding....[The twins] just burst into a smile, it's more than just a smile really--it's beaming--it's just like you see them just light up! They've now gotten to the point where they can hug...That's definitely a real high when you pick them up and bring them up to your shoulder, and they wrap their arms around you and hug you. Though, I realize, a lot of that's probably just for the 'I want to hang onto something' type of thing, but it's certainly quite nice** [chuckling]. (B-2)

Making the baby laugh and keeping him happy were very important aspects of the relationship development for these fathers.

> **Find out what would make them laugh. You know, at the starting that's, in my mind, a lot of [relating] is just what makes them laugh so that they're happy and so on.** (B-2)

> **When they are babies you are always in there trying to tickle them, wake them up. I was always getting into trouble for that....It's kind of a tie with them. You know...he laughs a lot more and it makes you feel good when you see him laughing.** (A-2)

Another very enjoyable aspect of their relationship with the baby were the play times. Fathers could act "childish" and feel young, while enjoying the interaction with their baby.

> **He does his little giggles** [chuckling]**....Actually I get pretty childish myself....He'll see me doing something, [my wife] pointed out, then I'd turn and look at him and he's doing exactly what I was doing.** (E-2)

> **Certainly playing with them--there's definitely a high....It's something I could do for a long time....Work has been extremely intense in the last while, but it's still lots of fun to know that you're going to play with [the twins] and so that certainly keeps me going....You don't have kids to just watch them or sit back and observe or something, you want to interact with them and have fun with them, and, to a point, it helps keep us all young.** (B-2)

The babies' enjoyment of play also encouraged the fathers to interact with them.

> [Re: things the father liked best about the baby] **I like his playfulness.** (E-2)

> **I think playing on the floor, like kind of play fighting, wrestling that kind of stuff....That's the fun part--taking him on the floor, rolling around and being his daddy.** (C-2)

Enjoyment of play with his father was cited as evidence of a father-infant relationship for one of the fathers.

> **[An evidence of relationship between my son and me is] I guess that he loves to play the games. Like he knows what the games are and he loves to do those things.** (B-2)

Finding Meaning in Helping the Development of Their Baby

Playtime for these men had more functions than just to provide pleasure for the father and the baby. Based on several studies of fathers and infant interaction, Meyer (1986) concludes that playtime may be the most influential way that fathers encourage a child's development--physically, psychologically and socially. These fathers certainly seemed to be aware of the potential of play for enhancing the baby's development. They became very adept at using playtime efficiently to incorporate exercise and to encourage their babies to try new things. Some had received instruction from physiotherapists, whereas others used their own reasoning to invent games which accomplished development goals while also providing pleasant experiences for the baby.

> **If it's not work, it's home with [my son]--playing with him, trying to help his disabilities....The physiotherapist tells what to do...how to bend his knee, and different ways how to change him due to his hip structure and all that stuff....Tease him when he's like trying to crawl because he's going to have problems crawling,...put his favorite toy in front of him and make him crawl to it. Arm motions, his eye motions, all that stuff--like when it's not work, it's here, helping him out, trying to help him cope.** (C-1)

> **Just between me and him we had this because every morning when I, at 7:00 o'clock, take him downstairs....I'd make sounds and he'd just look around because I wanted to make sure that he could follow me around with his eyes and his head....**[The physiotherapist advised] **if he's in the bathtub, splash him and move his legs up and down, move his arms and that, and that's all I did. Even when I'd lay down on the couch with him, or I had him on the floor with a blanket I'd play with him like that with his legs....because I thought it was very important. I figure it's more that'll improve his legs. I'd rub down the back of his foot and say, 'Hey!'** [the

> father made a motion of pulling his foot back rapidly as if it had been tickled]....**[Sometimes] I seen him twitch and he'd cry and it was like I know he's in pain, but what's happening? What can I do? So I just done this** (massaging motion) **on my own.** (D-1)

> **One of the games that we love playing is 'Big and Strong.'...It's when you go to stand them up and they're kind of standing on their legs...[he] is catching on to it, but he can't keep his legs held straight for very long....We play an awful lot of visual eye games which is basically me bringing my face up to him or bringing him up to my face and we shake heads or something and he just laughs and laughs.** (B-2)

The men looked for progress in their baby's development, and one father even described the areas of delayed development as frontiers as if these were areas which yet would be conquered by his efforts.

> **I call [another game] 'Funning His Feet'--...each night...getting his feet out of his splints and massaging his feet and working his ankles...trying to get him to feel the movements,...so that maybe he will begin to think about, 'Well, how did that happen, could I do that?'...You can tell by the way that he's looking down at his feet that he can feel it and he knows that there is something going on...So, I...try and tickle him a little bit and I don't just play with his feet and ignore him, so to speak, so that there's some fun that he still has....So far, there just seems to have been solid progress. So at this point we are just kind of hoping that he will be able to gain a greater control with his legs and his feet and ankles and so on. It's, I guess, the last frontier, so to speak** [chuckling]. (B-2)

Seeing advancement of his child gave each father a sense of satisfaction and pleasure.

> [Re: the most rewarding or pleasurable thing about being a father] **Well, you see how they advance and teach them stuff.** (A-1)

Others people, however, could decrease the father's self-esteem by not giving him social permission to be active and helpful in his baby's life. One father in this study jokingly commented about others' judgements about his child care abilities: **"You get these looks like you are a man--you are useless!"** (B-1) He chuckled after the comment, but when asked how he felt about that attitude, he seemed to suggest that he felt misunderstood and obligated to justify his actions.

> **Well, it's kind of like, I can help. I certainly try and help....I guess they figure, [the father] goes either out and plays sports or the bars or something, and I don't have time for either one of those.** (B-1)

Finding Meaning in the Legacy of the Relationship

Two of the fathers spoke about the legacy they were leaving the world because of their relationship with this child who would hopefully live on after the father's death and continue in the traditions, beliefs, and values that his father had taught him.

> [A fun thing about being a father is] **knowing that you passed your genes on to the next generation....Our culture is very important. I'd like him to learn that first hand...beliefs....My kids, they all sing Pow Wow....I teach them everything about music, their culture....I sing to [my son]...in actuality it is a story, you know....I get a real sense of accomplishment from teaching my kids things. I don't know, it...makes me feel good inside.** (F-1)

> [The most important parts of being a father are] **the opportunities to raise kids that...know what you know and are there to, you know, carry on...the work that I'm doing in terms of the world...through our church--...[kids] that care about other people and try and help and understand what's right and wrong.** (B-1) **You certainly hope that the end process is that you raise an independent, self-thinking, self-motivated person who will go out and make the world better in some way**. (B-3)

In summary, the fathers found meaning in the closeness and pleasure of the relationship and through being recognized as someone special whose company was enjoyable. They found meaning in being able to help their child to develop his potential and in being able to leave to the world a valuable legacy because of their relationship with this child. The importance of the father's actions which helped his child's development and the future contribution to the world made it especially important for the father to be there for his child. And the pleasure and satisfaction that relating to his child gave to each father made it easy and desirable to be there for his child.

Summary of the Four Subprocesses

As the fathers experienced the four subprocesses of committing himself to being the father of this child, getting to know and be known, looking beyond the situation, and finding meaning in the relationship, they worked through the emotions and tasks necessary for them to fully and effectively be there for their child and develop a father-infant relationship which was described as close and satisfying. The most notable hindrances to the development of this relationship were separations from the baby, interference with the fulfilment of the roles they desired to play in the baby's life, and emotional burdens they experienced. The two most troublesome emotions which the fathers experienced to varying degrees were helplessness and hopelessness. The fathers actively combatted helplessness by developing a helpful role and hopelessness by employing strategies which built and maintained hope.

CHAPTER V -- DISCUSSION AND IMPLICATIONS

This grounded theory study of the experiences of six fathers of infants with spina bifida was intended to answer two research questions:

> 1) How does the father-infant relationship develop between a father and his infant with spina bifida?
>
> 2) What factors help or hinder the development of the father-infant relationship with an infant who has spina bifida?

The data gathered to answer these questions were used to identify, describe, and begin to formulate theory about the development of the father-infant relationship when the baby has spina bifida.

The reader will note that many references are made in this chapter to Anderson (1994) and Anderson (1990). This is because these two researchers' studies bore the most similarity to my own, although the study populations were different. A preliminary report on the study by A. Anderson (1994) initially stimulated my interest in investigating the process of father-infant relationship development with fathers of infants with spina bifida. I sought her advice throughout the process, but I considered her findings as bracketed material while gathering and analyzing data and did not assume that my findings would be either similar or different. I did not discover the unpublished thesis by G. Anderson (1990) until after the analysis of my data, but noted that some of her findings about parents' processes of dealing with potential genetic abnormality of their babies before birth were quite similar to my own.

The basic social psychological process of "being there for my baby -- no matter what" involved four subprocesses: a) committing himself to being the father of this child, b) getting to know and be known, c) looking beyond the situation, and d) finding meaning in the relationship. Developing a helpful role and building and maintaining hope were strategies used to combat helplessness and hopelessness in order to be there for their babies in the manner in which the fathers desired.

The findings of my study suggest that a consistent and somewhat predictable process takes place as the father-infant relationship develops. Much of the fathers' experiences were the same as those observed with fathers of healthy infants, but some experiences were very different because of their babies' health conditions, health care, and the health teaching which the fathers received. Many of the factors which were identified as either helping or hindering the development of the father-infant relationship can be either encouraged, changed, or improved through increased attention by health care workers to the process of relationship development.

In this chapter, I will examine the research findings and their relationship to concepts in the literature organized according to subprocesses. The major influencing factors and coping strategies will be discussed within the subprocess category which they influence the most. Practice implications for health care workers will be addressed, strengths and limitations of the research will be stated, and recommendations for further study will be suggested.

Being There for My Child--No Matter What Happens

L'Abate (1992) discusses being there in a loving relationship, saying, "Loving someone means being able to Be with them when they hurt so that they can Be close to us when we hurt" (p.201) [capitals present in the original quote]. The relationship which the men desired definitely included the hope of future reciprocity between the father and infant. "Being there" involved the father's physical presence, so these men chose to be involved with the baby even when most of the interaction was one-sided. The fathers wanted to encourage the baby to trust them so that a relationship which could transcend physical separations might be developed. Since the fathers hoped that being there for their child would result in their child being there for them, they looked for evidence which showed that the baby really knew they were there and considered them as special people whose presence was enjoyable to them. Though these fathers truly hoped to establish such a reciprocal relationship, it was evident from their comments that they intended to completely fulfil their portion of the requirements of being there for this child, even if the disabilities of the baby prevented him from responding in a reciprocal manner because they perceived this as the measure of their success as a father.

Being there in a permanent and unconditional relationship to this child involved sacrifice. This is consistent with the findings of Sproul (1987), Van Cleve (1989), and Loebig (1990) who documented sacrifice to the point of self detriment among parents of children with spina bifida. Sacrifice was most evident in my study in the fathers' comments about the importance of time with the baby, their stories which revealed patient endurance of emotional distress for the sake of the baby, and in the changes they chose to make in their lives in order to be the best fathers they could be. Being there involved more than a one time commitment. It required choosing over and over again, in individual situations, to act in accordance with the goal of "being there for my child--no matter what."

Committing Himself to Being the Father of This Child

Before the Prenatal Diagnosis

Committing themselves to fatherhood resulted in a transition process involving some uncertainty and many personal and lifestyle changes for the men. Osherman (1986) describes fatherhood as both a "healing and wounding experience" (p. 150) as he discusses the internal work of men deciding to commit to fatherhood. His descriptions of the introspection, emotional work, and anxieties that men generally experience during the transition to fatherhood are remarkably similar to the ideas expressed by the men in this study. Some of the men in my study demonstrated anger or a sense of helplessness when speaking of their own fathers. It was evident that the process of considering what fatherhood means opened some old scars from their own childhood days. The opportunity to choose their own fathering styles, however, seemed to give them hope that they would not repeat their own father's mistakes, and making this choice offered the men a possibility of emotional healing through the relationship with their own children.

The fathers in my study described self-evaluation in light of their ideals of what a father should be, some ambivalence about the responsibilities involved with raising a child, and some anxiety about learning new skills--all of which were consistent with the findings of several studies of the transition to fatherhood of a normal baby (e.g. Cowan, 1991; May, 1982; Cronenwett & Kunst-Wilson, 1981). Persistent emotional struggles and ambivalence about fatherhood were expressed by only one father and this was resolved by the time of the birth. May (1982) found that, even though experiencing ambivalence during the pregnancy is common, most men are able to resolve the doubts before the baby is born.

After the Prenatal Diagnosis

After the prenatal diagnosis, however, the experiences of the fathers in this study diverged greatly from those described by fathers of normal babies. The worst part of the waiting according to the fathers of babies with spina bifida was the uncertainty about how severe the babies' disabilities would be. Phrases like "waiting for the judgement day" or "a nightmare waiting to happen" vividly portray the suffering such prolonged uncertainty produced. Uncertainty was also a recurrent theme in Anderson's (1990) grounded theory study of parents coping with fetal genetic risk. Anderson described her participants as "'hoping for the best,' but 'fearing that the worst may happen,'" (p. 64) while they waited for the baby to be born. Closely coupled with the idea of uncertainty during the pregnancy was a feeling of "powerlessness and helplessness," which seems to lend support to my findings that feelings of helplessness troubled the fathers during the prenatal period after they had been notified of the spina bifida (Anderson, 1990).

Only one father in my study described an emotional attachment to his baby before birth. He attributed this to relating to the baby prenatally--by talking to him and stimulating him to move. This is consistent with the findings of Condon and Dunn (1988) who noted that a few parents develop an emotional attachment to the fetus before birth and of Anderson (1994) who found that the beginnings of father-infant relationship development may occur before birth. The fathers in my study who had received prenatal diagnosis information, however, did document much emotional investment in the baby prenatally, due to the emotionally intense committing process they experienced after the diagnosis. Jordan (1990) said that the fathers in her study tended to gradually feel as if the child was becoming more real to them during the pregnancy and the first few months postpartum. Only one of the fathers in my study expressed difficulty with getting used to the idea that he had a "real" baby, even after the birth. Through the time period that the other men were experiencing emotional turmoil related to the prenatal diagnosis, he received no ultrasound evidence, had no idea that anything was wrong with his baby, and was still dealing with his occasional ambivalence about becoming a father for the first time. The four fathers who were informed prenatally definitely knew that their babies were real, since they had seen them on ultrasound recordings, discussed their baby's problems with the physicians, and, in some cases, struggled with the idea of therapeutic abortion. Anderson (1990) noted that there was a greater sense of the reality of the baby among parents who have experienced prenatal ultrasonography. The uncertainty of the baby's prognosis, however, still shrouded the baby in mystery and made the waiting stressful for the fathers. This finding is supported by Folkman and Lazarus (1988) who say that "An ambiguous state of affairs is often more stressful than knowing even the most negative outcome" (p. 312). Even hearing the worst-case scenario did not give the fathers a sense of certainty of the outcome while waiting for the birth.

Factors Influencing Committing Himself to Being the Father of This Child

The fathers identified the presentation of worst case scenarios by physicians without adequate information and support and feelings of sadness and helplessness as factors which negatively influenced the subprocess of committing to being the father of this child.

The presentation of worst-case scenarios, rather than a range of possible outcomes, and the delaying of referral to the Spina Bifida Clinics for information until after the birth of the child caused the men a great deal of suffering and increased their anxiety about committing to being the father of this child. A look into a future of only bleak possibilities seems to be one of the cruellest torments a person could experience. Yet, that seems to have occurred for some of these men. Perhaps health care workers are just waiting to see whether the child will be born alive, or perhaps prenatal diagnosis is such a recent phenomenon that health care workers have not developed a definite and consistent strategy which includes prenatal referral to a Spina Bifida Clinic. The fathers in my study wanted to know about spina bifida prenatally so that they could prepare appropriately. Referring parents whose baby later dies in utero could still serve a useful purpose for the parents in answering their questions about spina bifida and the possibility of its occurrence in later pregnancies.

Thoits (1991), in a comparison of studies of gender differences related to coping, concluded that problem-solving strategies occur more frequently for both genders in situations in which the persons experience a strong sense of "control, power, or responsibility" (p. 109). Worst case scenarios presented prenatally to the fathers of my study prenatally mainly resulted in feelings of powerlessness and helplessness. If health care workers are to encourage healthy relationship development and healthy family functioning they must pay attention to how the news they relay to parents affects their sense of control and hope. The lack of attention to the importance of hope as a sustaining force for human beings (Jevne, 1993) was evident in the preponderance of overly negative content that the fathers in my study had received from health care workers. The men in my study experienced feelings of hopelessness over a long period of time. Gottschalk, Fronczek, and Buchsbaum (1993) found different distinct and measurable neurobiological changes within the brain which occurred in response to situations resulting in feelings of hopefulness and other situations resulting in feelings of hopelessness. The lasting physiological effects of prolonged hopelessness are unknown.

Sadness was experienced by the fathers in my study from the moment of the prenatal diagnosis. Loss of dreams seemed to be very significant for these men. Dreams such as having a baseball star for a son did not seem to be easily relinquished--as indicated by one father's comment that his son would be swinging the baseball bat even as he acknowledged that his son probably could not play baseball and would have to find some other area in which to excel. Uncertainty about the extent of the damage made the grief during the pregnancy especially potent because the fathers were uncertain of what they could dream which might be achievable with this child.

Two of the fathers in my study described a reticence to talk to others about the situation during the pregnancy because their child might be born dead--a finding which Anderson (1990) also reported in her study of parents who had undergone prenatal diagnosis because of some type of genetic risk. Such reticence to talk to others resulted in social isolation, and this seemed to increase the burden of the grief for one father. Those fathers who had a good support system and who were able to accept social support in times when sadness was strongest seemed to cope more effectively with their feelings which allowed them to move on to other concerns--a scenario which is well-documented for mothers of children with handicaps (Johnson, 1988; McAndrew, 1976).

It was evident that sadness could affect the relationship development. One father, whose baby's condition was serious at birth, described a perceived need to protect himself from feeling intense grief by holding back at first, rather than becoming deeply emotionally attached to his son. This was very similar to the findings of Scheers, Beeker, and Hertogh (1984) who documented a parental emotional resistance to attachment to infants with spina bifida whose prognosis was poor.

Teel (1991), in a concept analysis of chronic sorrow, suggests that the sadness associated with the loss of a perfect fantasy child may persist and recur. My study did not cover a long time period, but I would expect that the fathers may experience some sadness at times in the future when other aspects of their dreams for their children become clearly unachievable. My findings, however, were different from those in studies of chronic sorrow among mothers of children with spina bifida. Burke (1989) found that deep chronic sorrow with definite depressive elements was common among mothers of children with spina bifida throughout the childrens' lives. The sadness of the men in my study seemed to relate mostly to their dreams and expectations of their children. The fathers demonstrated a willingness to consider alternative dreams and to adjust their expectations, which would suggest that they may cope with the sadness in a different way than the mothers. Thoits (1991) relates findings that men tend to react more with physical symptoms than mental symptoms in response to stress, whereas, women react in the opposite manner. Longitudinal studies of sorrow in fathers of children with spina bifida would be necessary to determine how fathers' and mothers' experiences may differ.

Developing a helpful role was an effective strategy for combatting feelings of helplessness. Preparing for a helpful role not only kept the father busy and distracted him from focusing on difficulties prenatally, but was important in maintaining his self-esteem. The men's frequent comments about wondering how they could help, or what they could do when problems arose reflected a strong sense of self-efficacy as described by Bandura (1982). They were accustomed, as one father said, **"to taking problems on [themselves] and solving them."** Perhaps perceptions of self-efficacy partially explain the refusal of some of the men to prenatally accept the possibility that the baby's condition could be as bad as the physicians' presentation of the worst case scenarios. To accept such news seemed to be equivalent to agreeing that they could do very little to help their child. Developing a helpful role helped the fathers to cope because it presented opportunities to experience some sense of mastery in the situation. Taylor (1983) described a similar finding among women who were faced with largely uncontrollable life events. Finding some aspects about which the women could do something helped them to cope with feelings of helplessness even concerning the areas over which they had no control. Cohen (1993) described a human need to sense societal permission to have a helpful role. This permission seemed to be either granted or denied by the actions and words of health care workers. This granting or denying of permission was similar to Cherry's (1989) finding that health care workers, by their words and deeds, could ameliorate or exacerbate the stress for parents of children with handicaps.

Getting to Know and Be Known

One of the earliest ways the fathers used to get to know and be known by the baby was through being there to meet and greet the baby, being there as a protector, being there as a comforter, and being there spending quality time with the baby. The major factors which negatively influenced the subprocess of getting to know and be known were restrictions to relating to the baby in the manner the father desired. These restrictions were related to hospitalization and treatments and the time constraints of employment responsibilities. Wives and the fathers' learning about his baby and the required care most positively influenced the fathers' process of getting to know and be known.

Being There to Meet and Greet the Baby

Most of the phenomena of engrossment as documented by Greenberg and Morris (1974) was vividly described by the fathers in my study. The intense desire to see, touch, and study their infants was present, but the opportunity to do so was delayed by medical treatments. The fathers also described joy and pride, but these feelings also were delayed for some of the fathers due to apprehension about the baby's condition. The only aspect of engrossment as documented by Greenberg and Morris (1974) which was not described by the fathers in my study was awe at the baby's perfection.

My findings about the fathers' interaction with their babies were very different from those of Condon and Dunn (1988), Levy-Shiff, Sharir, and Mogilner (1989), and Anderson (1994), which suggested that the fathers might not interact much with their babies because of their imperfections and possible lack of fulfilment of the fathers' expectations. The fathers in my study were very active with their babies. Perhaps, for the fathers who knew about the spina bifida prenatally, the process of rebuilding dreams with more achievable goals resulted in changes in the fathers' expectations by the time the baby was born. However, the two fathers who were given the diagnosis at birth were also very active with their children. These two fathers seemed to experience a progression much the same as that experienced by the fathers who knew prenatally. Consideration of what being the father of this child means, commitment, and development of a helpful role occurred for all of the fathers, but the progression happened over a shorter time period for the fathers who found out about the spina bifida at birth. The unexpectedness of the discovery of spina bifida at birth tended to result in feelings of shock for the fathers at the birth and sadness came later for those two fathers when the shock wore off. My findings suggest that the fathers' expectations of the baby may be changeable and may not necessarily hinder the development of the father-infant relationship if the father is not hindered in his progression through the process by other factors.

For the men in my study, touching was an important part of meeting and greeting their babies. As was previously discussed, there is still debate in the literature about whether a biologically-mediated process requiring early skin-to-skin contact with their infant brings about bonding for fathers, and this study was not designed to measure or describe bonding or attachment. Toney (1983) in her bonding study of 37 first time fathers of normal infants found that ten minutes of holding the baby during the first hour after the birth resulted in no significant difference in bonding behaviors of the fathers from those who did not hold the baby during that time period. Bonding and attachment debates aside, however, the fact remains that holding their babies early had meaning for the men in my study, and denial of the opportunity to do so resulted in profound disappointment. Perhaps holding or at least touching earlier might have helped the fathers to overcome the sense of unreality of the situation which some of the fathers described. Osherman (1986) speaks of the emotionally healing effects for the father of holding his baby when he says, "An infant holds the father as much as the father holds the infant" (p. 153). Some fathers' statements reflected a reticence to interfere in the physicians' world and a tendency to just stand back and watch. The results of the study of 24 fathers during delivery (Tomlinson, Rothenberg, & Carver, 1991) supported this observation--fathers did tend to stay in one spot and not to touch unless they were told they could do so. Perhaps they could have had more opportunity to touch the baby, if only to stroke the baby while some procedures were being done because touch meant so much to these men. Perhaps health care workers need to make a conscious effort to give fathers permission to touch even babies who have serious defects.

Being There as a Protector

The very protective feelings described by the fathers of this study seem to be similar to the findings of many researchers who have studied the transition to fatherhood (e.g., Cowan, 1991; Cronenwett & Kunst-Wilson, 1981), but the idea of protecting the baby as a way to build up the trust needed for development of the father-infant relationship was a very logical, but new, facet of the protector role which I had not considered. For the fathers in this study, being there as a protector for the baby involved much more threatening situations than are usually encountered surrounding the birth of a normal child. Thorne and Robinson (1989) documented the "guarded alliance" that exists between family members of people with chronic health problems and health care workers as involving a trust dimension and a competence dimension, both of which influence the interactions between the involved persons. This seems to describe the uneasy partnership which at times existed between the fathers in this study and health care workers. When the threat or pain for the baby exceeded the perceived benefits, or when the fathers thought that the health care workers were incompetent, that protective self, illustrated by the eagle or the mother bear analogy, was allowed to show. The fathers of my study sometimes felt the need to protect by protesting. This was consistent with the findings of Burke, Kauffmann, Costello, and Dillon (1991) that parents of hospitalized children restrained themselves until they felt they could no longer allow incompetence or danger to threaten their child and then they firmly "took charge" of the situation. Park (1991), in her study of parents of hospitalized children, documented a similar reaction of parents to inadequate care, which she described as parents "liberating themselves," for the sake of the baby.

Being There as a Comforter

Comforting his baby served multiple functions, for both the baby and the father. Comforting could combat helplessness because one could often comfort when absolutely nothing else could be done. Satisfaction derived from the accomplishment of comforting was also very important for the fathers' self-esteem--one father described it as "feeling like a millionaire." But, perhaps the most significant contribution of comforting for these fathers was the development of the relationship by showing the baby that the father is there for his needs--no matter what happens.

Cronenwett and Kunst-Wilson (1981) described role conflict as a source of stress for fathers and this was very evident in my study as the fathers were at times frustrated by being hindered from their desired role of being there as a comforter for the baby. Keeping the fathers away from their children during painful procedures and while they are awakening from anesthesia may cause more suffering for the fathers than watching the procedure would and it may interfere with father-infant relationship development. The fathers in my study seemed to equate not being allowed to comfort the baby as a hindrance to fulfilling a vital part of their role as fathers and as a possible breaking of the trust relationship between the baby and his father--illustrated by comments about the baby wondering where his father is when he needs comfort.

Being There Spending Quality Time With the Baby

According to these fathers, being there for the baby in the manner they desired required spending considerable quality time with the baby. The time taken up in medical treatments interfered with spending quality time and trips to and from the hospital also took a lot of time. Work and other responsibilities interfered at times with spending the amount of quality time they desired with the baby. The fathers of my study chose to make adjustments in their use of time for the sake of the baby. Bradt (1980) asserts that incorporation of another family member may require adjustments within the family in order to develop healthy relationships. Anderson (1994) labels the process involved with adding a family member as "making room for the baby" (p. 97) and describes it as having both psychological and physical aspects. In this particular study, these sorts of adjustments were most evident in the efforts these men made to change their work situations to have more quality time with the baby. These changes ranged all the way from working more efficiently to changing jobs. The fathers' pride in accomplishing a role which helped the baby, either to develop, to learn, or to be happy seemed to indicate satisfaction in their use of time with the baby. Cohen (1993) noted an interesting finding along this line--that men identified being a father or a husband as more important than their employment role.

The fathers in my study indicated that their wives influenced the development of the father-infant relationship positively by helping them to spend quality time with the baby. This finding is consistent with those of several researchers (McConachie, 1994; Parke, 1988; Parke & Tinsley, 1981; Stevens, 1988). The wives encouraged the development of the relationship by being generous gate-keepers who arranged time for the father to be alone with the baby, by relaying interesting information about the baby to the father, by reminding the baby about the father when he was absent, and by helping the father to comfortably develop competence in baby care and interaction.

Pedersen (1982), Thurman & Korteland (1989), and Clarke-Stewart (1982) describe many ways that wives may hinder the father from spending quality time with the baby such as: competition for the baby's favor, denial of access to the baby, and criticism of the fathers' attempts to interact with his child care. None of these hindering actions were described by the fathers in my study except in the case of the one father who was separated from his wife and seeking access to his son through the legal system.

It was very evident that the fathers' learning about child care and spina bifida helped the development of the father-infant relationship. Jones and Lenz (1986) found that fathers' self-perception of competence in child care was directly proportional to the amount of their interaction with their babies. The frustration the fathers in my study described when they did not know what to do for their babies contributed to feelings of helplessness and lack of competence in an already challenging situation and made interaction uncomfortable. But knowledge made interaction with the baby easier because it allowed the fathers to overcome feelings of helplessness and hopelessness. Farran, Herth, and Popovich (1995) suggest that hope primarily improves human functioning through more effective use of energy than occurs with hopelessness. Generally the men relied heavily on their wives for help in learning about baby care, but nurses also were described as sometimes being helpful to the fathers' learning.

Looking Beyond the Situation

Looking beyond the situation for the fathers of my study involved looking beyond the present and looking beyond the disability. Looking beyond the present by dreaming of a positive future for their babies helped the fathers to be more comfortable during the time early in the babies' lives when frustrations were many and relationship rewards are few. Looking beyond the disability allowed them to combat hopelessness by building and maintaining hope.

Looking Beyond the Present

Brazelton and Cramer (1991) suggest that parents' view of the baby as attractive and perfect may help them to endure the limited rewards in the parent-infant relationship in early infancy because the parents dwell on the future potential of the child. Similarly "looking beyond the present" helped the fathers in my study to endure present frustrations and lack of relationship rewards in the early infancy period. In my study, however, the process of looking toward the future seemed to take precedence over attention to aspects of attractiveness or perfection. This is not to say that they did not see their children as attractive, charming, and thoroughly delightful, but only that the thoughts of the fathers in my study seemed to be directed toward the future to a greater extent than was documented for the fathers of normal babies by both Brazelton and Cramer (1991) and Anderson (1994). None of the fathers in my study commented on their baby's perfection, although some new fathers seemed amazed at the baby's abilities; but all of them commented on evidence they saw which indicated that their baby had much potential for future development.

Looking Beyond the Disability

Feelings of hopelessness troubled the fathers early in their babyies' lives. They combatted hopelessness by using strategies which built and maintained hope such as replacing negative ideas and maintaining an acceptable level of uncertainty. These strategies involved a lot of effort on the part of the fathers to look for positive aspects, signs of progress, and success stories which implied that their own babies might have a positive future as well. Scott (1994), in his research about hope in families of schizophrenics, found that "putting energy towards hope" was one way for family members to move "beyond devastation" (p. 47). Although the disabilities are totally different, a similar strategy seemed to be evident in the choices the men made in this study, in order to move beyond the devastation they experienced initially because of their child's anomalies. As one father described it, they could either dwell on the sad aspects of the situation which would result in "one hell of a long life for [the man] and [his] family," or they could choose to deal with it by building and maintaining hope. Cowan (1991) found adequate coping to by very important to avoid being overwhelmed and incapacitated by emotions which result from difficulties in life.

Farran, Herth, and Popovich (1995) describe hope as a rational process which includes formation of goals, consideration of resources, active problem solving, exercise of control over life experiences, and the element of waiting for expected outcomes. In contrast, they consider hopelessness to be irrational because it results in emotional blindness to positive aspects, available resources, and possible solutions. If hope truly is a motivator of action, a conserver of energy, and a logical coping strategy, then it seems that more attention should be paid to encouragement of hope in fathers of babies who have spina bifida.

Seeing positive aspects seemed to be a very important foundation for building and maintaining hope. Fosdal (1992), a nurse who has spina bifida, vividly described his own father's urgent need to hear good news from the physicians soon after his birth. "No positive comments were offered until a physician commented on my 'good sucking ability.' This comment alone gave my father hope and helped him relax for the first time since the beginning of this crisis" (p. 287).

Seeing the positive aspects resulted in more positive emotions for the fathers in my study and helped them to keep fulfilling their helpful role. Scheier and Carver (1985) describe positive emotions as very important for coping.

> First they act as 'breathers' allowing people to take a break from the demands of coping. Second, positively-toned emotions like hope and positive anticipation can act as 'sustainers' of action, causing persons to persist in their coping efforts even when situations become extremely taxing and demanding... (p. 244)

Folkman and Lazarus (1988) also state that "Positive reappraisal of events can generate benefit emotions such as pride and satisfaction, and perhaps reduce harm emotions such as anger and sadness" (p. 312).

The fathers of my study found that current information and religious beliefs and prayer were important resources for building and maintaining hope. Current information, especially about medical advances, provided positive input which served to build hope for a better future situation for their baby. This additional positive material helped them to reframe the situation seeing it as a challenge rather than a tragedy--a strategy which is described as an effective coping mechanism in situations in which action is necessary and negative aspects are prevalent (Folkman, 1991). Prayer and religious beliefs seemed to help the fathers to build and maintain hope in several ways. Some men were able to reframe the baby's situation to see it as involving both blessings and challenges from a good God. Religious beliefs could help them cope when they felt hopeless because they could trust a more powerful being and there was always the possibility of miraculous intervention. Prayer combatted helplessness because it was something the men could always do and because they believed that their prayers did bring about results. Park and Cohen (1992) support the idea that religious coping can be an effective way for some people to deal with difficult situations, but they were unable to find consistent empirical evidence of effectiveness in coping across many studies. My findings also indicated that the mens' religious beliefs and prayer practices were as diverse as the men themselves and there was no consistent pattern which I could identify other than to say that all of the men except one found religious beliefs and/or prayer to be helpful for the building and maintaining of hope.

Maintaining an acceptable level of uncertainty helped the fathers of my study to build and maintain hope. By refusing to think of some things now or to plan ahead, some of the fathers seemed to be practising denial and, therefore, could be perceived as coping inadequately, but Auerbach (1992) suggested that such a practice may actually be an effective coping strategy.

> This is because preoccupation with potential misfortune exacts a cost in diminished flexibility and spontaneity, delay of gratification, and limitation of one's range of potentially reinforcing activities....overall, we tend to compartmentalize and attend to stressors on our immediate temporal horizon. (p. 135)

Not wasting energy on future worries can preserve energy for present activities. Lazarus and Lazarus (1994) described hope as "a state of mind in which the positive outcome has not yet occurred" (p. 69). This suggests another possible reason for maintaining some future uncertainty--if a negative outcome has not yet occurred, then a positive future outcome may yet be possible.

Finding Meaning in the Relationship

The fathers in my study found meaning in the closeness of the relationship, in being recognized as someone special, in the pleasure of the relationship, in helping the development of their baby, and in the legacy they would leave behind because of their relationship with this child. Lazarus and Lazarus (1994) speak of man as an emotional and rational creature who needs to make sense of occurrences and emotions in life in order to maintain mental health and to be happy. Finding meaning in the relationship helped the fathers to make sense of this situation and to be more comfortable interacting with their babies. Whereas, in the early days of the infant's life much of the interaction of the fathers in my study with their babies seemed to be motivated by the commitment the father had made, finding meaning in the closeness, pleasure, and significance of the relationship made interaction very desirable. Anderson (1994) described a similar finding. She found that fathers of normal babies described interacting with their babies both because of a sense of obligation because of the babies' vulnerability and helplessness and because they wanted to get to know the baby. Anderson (1994) found that when the babies were able to respond actively to their fathers the interaction became less a matter of "having to" than "wanting to." Responsiveness was an important aspect of finding meaning in the relationship for the fathers in my study because the responsiveness of the baby showed the father that he was someone special whose interaction was enjoyable to the baby.

All of the fathers in my study acknowledged a close and emotionally satisfying relationship with their babies by about two months of age based on the baby's responsiveness to his father. This finding differs from that of Anderson (1994), in which the fathers clearly identified development of the father-infant relationship with their normal babies by five-six weeks after the birth. Because not all of the babies in my study evidenced developmental delays, the infants' mental functioning would not explain the difference in time required for relationship development. Klaus and Kennell (1982) and Rosenblith (1992) suggest that inhibition of the relationship development may occur due to environmental factors. Perhaps the prolonged separations and the fathers' inability to touch and hold their babies who had spina bifida as early as they desired may have slowed the process of relationship development. The fathers definitely feared that not getting to be with and to touch their babies enough might hinder the relationship development. They expressed worries that the babies might forget them or never develop close feelings for them because of the restrictions which were imposed by hospitalizations.

Being able to help their babies to develop provided meaning for the fathers in my study. Time spent in play was one way that fathers helped their babies to develop while enjoying the interaction. Play has been documented by many authors as a common and preferred domain for fathers (e.g., Parke & Tinsley, 1981; Pedersen, 1982) and as a valuable teaching tool for infant development (Williamson, 1987). That the fathers spent considerable time playing with their babies was not a surprising finding, however, the variety of games, the problem-solving evidenced in structuring the games to bring about developmental progress, and the amount of time spent in helpful play were unusual. It would seem that the desire to help their babies' development was another logical outgrowth of commitment to "being there--no matter what" and of the development of a helpful role. Although only two of the fathers spoke about their child in terms of a legacy to the world, the fact that they did speak of it at all is an acknowledgement of the value these fathers saw in their children, and of their commitment to help the child develop into a person whose contribution to the world would be positive. This finding is supported by Osherman (1986) who speaks about the meaning that making a lasting contribution to the world through their children holds for fathers.

Summary of the Discussion

The findings of my study suggest that all of the subprocesses which were described were necessary to help each father to fully "be there" for his child in the manner he desired. Each subprocess contributed necessary growth and learning for the next. "Committing to being the father of this child" involved introspection, planning, lifestyle changes, and some sacrifices which helped the fathers to put their own needs in perspective and to become the kind of men who were ready to begin to relate to their babies faithfully in roles which would help them to know and to become known to their babies. Some of the subprocesses were complementary. For example, just "looking beyond the disability" through replacing all the negative aspects with positive ones could have been counterproductive to father-infant relationship development. However, developing a helpful role--which had occurred as a part of "committing himself to being the father of this child"--contributed to the problem solving actions which were likely to bring about the positive goals the fathers had imagined while looking beyond the situation. And finding meaning in the relationship was a strong motivator to interact with the baby.

Strengths and Limitations of the Study

Purposive sampling was used. Participants were chosen for their ability to give relevant information, based on their own experience of being fathers of infants with spina bifida. The variety of ages, amounts of experience with children, educational levels, employment, and income levels strengthened the study, because the data indicated that the men responded in a similar manner despite differences in these factors. Although ethnicity was not considered in the demographic questionnaire, some of the fathers came from distinct ethnic backgrounds, including Aboriginal, French, and Italian. The finding that the process was consistent despite ethnic differences also strengthens the study. The very small size of the available and accessible population prohibited true theoretical sampling without excessively prolonging the study and this was a limitation, but the variety within the sample as well as the ability of the participants as informants provided much rich data for beginning substantive theory development.

A strength of the study was that the interviews obtained data across nine different age groupings of the babies. This presented a fuller view of adjustment and relationship development at different ages than a more limited sample would have allowed. One limitation, however, was that the access policy of the hospitals did not allow the first interview to occur for most of the fathers until after the fathers had already acknowledged that the father-infant relationship was well established and clearly evident to them. Earlier access during the first few weeks of the baby's life would likely have yielded further information about the beginnings of the relationship.

Inclusion of babies with a wide variety of severity, complications, and related deformities also strengthened the study because the fathers faced many different types of challenges and yet responded in a remarkably similar manner.

One notable limitation of the study is that all of the babies were male, in spite of considerable efforts to also find participants who were fathers of female babies. Only one father of a female infant met the criteria and was willing to participate, but he was not included because his infant's multiple severe unrelated anomalies in addition to spina bifida suggested too divergent a situation for consistency of the research focus. Whether the relationship develops any differently with male and female infants who have spina bifida is uncertain. Jones (1981) found that fathers had more positive perceptions of male infants who were highly irritable than of female infants who evidenced irritability. She also noted that fathers tended to verbalize more to girls than to boys. Further research into development of the relationship with both genders is indicated.

My knowledge and years of experience with Parent/Child nursing and perinatal complications helped to develop theoretical sensitivity for interviewing, coding, and analysis of data, which further strengthened the study.

Implications

Educational Preparation for Fathers

The men in this study reported difficulty at times in gaining the knowledge they needed to adequately prepare for and cope with the challenges associated with being a father to a child with spina bifida. Most of them found the materials from the Spina Bifida Association and Clinics to be very helpful, but related that these often were not given to them soon enough. Fathers sometimes had to sift through inaccurate and outdated information from health care workers in order to extract useful content. Inadequate understanding of treatments and procedures by the fathers resulted in frustration, anger, disagreements with physicians, and, in one case, refusal to consent to a surgery (a decision which could have endangered the child's mental capacity and survival). While it is acknowledged that no one can keep current on all health care topics, all health care workers can make an effort to find out who does have the necessary, current information and then promptly direct the fathers to that source.

Emotional preparation for these fathers was sometimes thwarted rather than enhanced by health care workers. Communication of the prenatal diagnosis, explanations of the anomalies, and discussion of future prognoses were sometimes delayed or interrupted, leaving these fathers fearful and uncertain for long periods of time. Referral to the Spina Bifida Clinics at some point after birth afforded no prenatal contact with other families who had experienced this situation, and therefore encouraged a sense of isolation and a perception of hopelessness. Presentation by physicians of the worst case scenarios to prepare the fathers led to hopelessness and an inability to prepare adequately for the birth of the baby.

Suggestions about how to improve the preparation that fathers receive were proposed by the fathers in this study:

1) acknowledgment by the physicians of the uncertainty of outcomes and presentation of a possible range of severity and prognoses.

2) referral to a Spina Bifida Clinic immediately on prenatal diagnosis for explanations, information, and continuing follow-up.

3) a home visit by someone from the Spina Bifida Clinic shortly after the prenatal diagnosis to provide further educational and emotional support to the family.

4) a video featuring fathers of children with spina bifida talking about their children and their experiences in developing a strong father-infant relationship.

Another suggestion for improvement of the educational and emotional preparation of these fathers would be production of a booklet designed specifically to be used by obstetricians during discussion of prenatal diagnosis of spina bifida. Data from this study suggest that acknowledgment of uncertainty of prognoses prenatally and inclusion of general ranges of spinal cord and nerve involvement could be helpful for fathers. One father suggested that the most commonly asked questions and answers could be included in such a booklet in order to ease the process of explaining the situation to other family members and friends. Note pages in which parents could jot down questions for discussion at the Clinic also could be helpful. The prenatal diagnosis booklet should conclude with a page which gives information about the first Spina Bifida Clinic appointment scheduled by the obstetrician's office as soon as possible after prenatal diagnosis. A support group, or, at least, the phone numbers of other fathers of infants with spina bifida who do not mind being contacted by expectant fathers, might also be useful.

Nursing Practice

Although nurses played only a small role in the development of the father-infant relationship, some of their contributions were positive and others could be improved. It was interesting to note that none of the fathers followed the nurses' suggestion of leaving a picture of themselves at the hospital for the baby to see while they were gone, and one father expressed distrust of the idea. Perhaps examination of the emergent process of relationship development during the newborn period might explain this choice. The fathers spoke about the importance of getting to know the baby and be known by him. They emphasized the ways they would like the baby to know them--as a protector, as a comforter, as someone whose presence was enjoyable, as someone the child could come to with any problem, as a source of guidance and knowledge, and as one who loves them unconditionally. All of these roles required activity on the father's part to demonstrate these aspects of themselves to the baby. No picture could convey this knowledge to the baby. The need for fathers to demonstrate themselves to their baby through actions in order to become well-known by the baby suggests that doing baby care in the hospital could be very important for the development of the father-infant relationship. Early in the relationship the baby would get to know the father as someone who brings about satisfying or comfortable feelings like a full tummy and a dry bottom.

Some fathers felt like outsiders in the hospital who were interfering in the work of the health care professionals. These feelings may have restricted the fathers' learning about their baby's care from the nurses. Helping the fathers to become comfortable enough to learn the information necessary for development of competence in care and self-esteem as a father seems to be an area for nurses to develop. The nurses in the neonatal intensive care unit who were described as diligently studying the spina bifida booklet in the presence of one of the fathers may have destroyed their credibility as a source of information about spina bifida by this thoughtless action. Spending a few moments in preparation before work could have averted the situation and could have increased the father's confidence in the nurses as a source of knowledge and increased his comfort when he had to leave his baby in the nurses' care.

Arrangement of group classes for teaching fathers about care of their baby as suggested by Crummette, Thompson, and Beale (1985) would be very difficult because of the long and variable hospitalization of infants with spina bifida and the variety of treatments that may or may not need to be taught depending on the severity of the anomalies. Individualized teaching of fathers seems to be a more viable alternative in situations in which the baby stays for extended periods in the hospital. Implementing a teaching plan, with careful documentation of the teaching which has been done and the skills which the fathers have demonstrated, might have eliminated some of the discomfort that the fathers described regarding the perceived expectation that they were to be performing actions of which they were unaware or uncertain.

Because improvements in prenatal diagnosis are allowing people to know about some anomalies months ahead of the birth of the baby, nurses must be aware of the needs of fathers as well as mothers who face the birth of a child who will be challenged. Providing accurate and current information, appropriate referral, a listening ear, and encouragement of strengths and coping strategies are all roles nurses can take to assist these fathers.

An understanding of the uncertainty inherent in coping with a baby with a disability and the stress and frustration it engenders should make nurses more thoughtful and patient with these fathers. Nurses need to look beyond the disability as well by acknowledging the normal characteristics of the baby and rejoicing with the parents over evidence of progress. Asking fathers questions concerning father-infant relationship development and how life at home with the baby is going, rather than just focusing on the development of the child, may present further opportunities for nursing support (McConachie, 1994). Reinforcement of father-infant relationship development can be done by emphasizing positive features, suggesting coping strategies, and pointing out evidence that a relationship development process is occurring.

Arrangement for private time with the baby in the hospital, consideration of the fathers' need to have a helpful role (taking into account possible insecurity about baby care skills), and praise of fathers' efforts are all ways nurses could encourage the development of healthy father-infant relationships.

Nursing Research

There is a distinct lack of information about how fathers cope with relationship development with their babies who have congenital anomalies. Greater knowledge of the processes involved would better prepare nurses to support effective coping strategies and to assist fathers to build strong relationships. Replication of this study with fathers of infants with other congenital anomalies, especially those which can be diagnosed prenatally, could contribute to a greater understanding of general processes of coping which contribute to the development of the father-infant relationship.

It was noted that the perspective of the fathers sometimes changed markedly between the first and second interviews. This was evidenced by occasional denials in the second interview of ever being concerned about something which they had mentioned as a concern in the first interview. Further studies in which nurses follow the fathers through the prenatal period might contribute additional information that could have been forgotten or minimized by fathers who were interviewed retrospectively.

Cultural variations in father's preferred coping strategies might also be a useful topic to explore. Some subtle variations were noted in the proportions of utilization of some types of strategies when comparing fathers of different ethnic backgrounds. This sample, however, was much too small to make any definitive statements.

Conclusions

The study was designed to answer two research questions:

1) How does the father-infant relationship develop between a father and his infant with spina bifida?

2) What factors help or hinder the development of the father-infant relationship with an infant who has spina bifida?

Through twelve tape-recorded, semi-structured interviews with six fathers, it was found that the fathers experienced a consistent and somewhat predictable process consisting of four subprocesses--a) committing himself to being the father of this child, b) getting to know and be known, c) looking beyond the situation, and d) finding meaning in the relationship--which resulted in "being there for my child--no matter what."

Commitment to being the father of this child occurred over a long time period from the man's childhood through to the end of the pregnancy. Prenatal diagnosis introduced additional emotional turmoil to the commitment process--resulting in feelings of helplessness until the father could develop his own helpful role. Getting to know and be known was a process which occurred from the birth through approximately the first two months, and involved the father showing who he is and demonstrating his trustworthiness to the baby primarily through being there as a protector, a comforter, and as one who spends quality time with the baby. Looking beyond the situation started before birth with the fathers' dreams. Looking beyond allowed the fathers to build and maintain hope by using several strategies which replaced negative thoughts and news with positive information, and which maintained some uncertainty to allow for positive changes in the future. Finding meaning in the father-infant relationship because of closeness, pleasure, satisfaction with his role in the child's development, and the sense of continuity offered by the legacy he leaves behind after his death strengthened the father-infant relationship.

By considering the process involved in father-infant relationship development as well as the factors which affect relationship development, nurses can encourage the development of strong father-infant relationships and avoid some of the behaviors which adversely affect father-infant relationship development.

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APPENDIX A

Topical Guide For First Telephone Contact

Introduction of researcher

Explanation of access to name and contact number from clinic

Brief discussion of project

Interview procedure

Time requirement

Answers to initial questions/concerns

Arrangement for interview time

APPENDIX B

Interview Guide

(Adapted from A. Anderson, 1994, with permission)

Fathers' Perceptions of the Infant and the Birth:
How would you describe your baby?
When did you find out that he/she had spina bifida?
Probes: Did you know prenatally?
    If so, what did you think about the baby before he was born?
    Was he/she as you expected him/her to be?
Tell me a bit about the birth.
Probes: What was it like waiting?
    What did you think about then?
    How were you treated?
    What happened around the baby right after he/she was born?
    How was your baby's condition explained to you?
    Did you have a chance to see, hold, be with the baby right after birth?
    How did you feel about the baby's appearance?
What changes have you seen in the baby since His/her birth?
Probes: Would you say your baby has a personality?
    If so, describe your baby's personality to me.
    How would you describe your baby's physical features?
    How would you describe your baby's behaviour?
    Does he respond to you as you expected he would at this stage?

Fathers' Perceptions of the Father-Infant Relationship:
How would you describe your interaction with your baby?
How has your interaction changed since birth?
Probes: Would you say you are developing a relationship with your baby?
    What reasons do you have for saying that?
    Is it important to develop a relationship with your baby?
    What is it like?
    How do you feel about the relationship?
    Do you have distinct feelings toward the baby?
    If so, would you describe them for me?
    Are there any changes in your feelings since the baby's birth?
    If so, would you describe them for me?
    When did you feel some attachment or affection for the baby?

Father's perceptions of the factors influencing relationship development.

Probes: What things have helped you to get to know your baby?

What things have hindered you in getting to know your baby?

Has you baby been hospitalized? Had surgeries?

How did you feel about others taking care of your baby?

What sort of help did you have to learn how to care for your baby?

Did you have any particular fears or concerns about this baby?

Was it difficult to relate to the baby because of fears or concerns?

Did anyone/book/program help you with the fears/concerns?

Do you feel you have had enough time with your baby to get to know him/her well?

How has the birth of this baby affected you financially, physically, mentally?

How do you feel about these changes?

Fathers' Perceptions of Themselves as Fathers:

What is it like to be a father of this new baby?

How would you describe yourself as a father?

What kind of qualities should a father have?

What kind of activities do you do with your baby?

What activities do you most enjoy doing with your baby?

Probes: When, where, how do you do these activities?

What are your thoughts and feelings regarding these activities?

How confident do you feel taking care of your baby?

What do you feel confident in doing for your baby?

What is most rewarding (or pleasurable) about being a father?

What is least rewarding (or pleasurable) about being a father?

What did you anticipate it would be like to be a father?

Were your expectations met?

Have you changed since the birth of the baby?

If so, in what way?

Has the baby changed your life in any way?

If so, what do you think about it?

How do you feel about it?

Fathers' Perceptions of Support:

How would you say others around you have affected development of a relationship between you and your baby?

Probes:

Spousal:How does your wife fit in all this?

How do you think your wife helps you in getting to know the baby?

How would your wife describe you as a father?

Social:How do friends, associates, relatives fit in all this?

Do you feel your friends or associates understand your situation?

Has your work been affected in any way since the birth of your baby?

Health care professionals:

Has your relationship with your baby been affected in any way by the health care situations you have been in because of your baby's spina bifida?

The fathers will be asked if there are any further ideas, questions, or comments he would like to discuss before the interview is terminated.

APPENDIX C

Demographic Questionnaire

Age of father:______________________ Age of mother:______________________

Marital status: (check one, please)
Single______ Married______ Common law______ Separated______ Divorced______

Highest level of education finished:
For father:______________________ For mother:______________________

Father's employment:____

Mother's employment: ____

Income group (yearly combined--please check one group):

$1-29.999 _________ $30,000-$69,999 _________ $70,000 and above _________

Age of Baby:______________________ Sex of baby:______________________

Order of birth of baby in family (first, second, etc): ______________________

Was spina bifida diagnosed prenatally? (check) Yes___________ No___________

If so, how long before birth?____________ Height of spina bifida: __________________

Has a shunt been inserted? Yes_________ No________ Number of times: _______

How many times has your baby been hospitalized including birth? ________________

Are there any people in your families who have spina bifida? ____________________

APPENDIX D

Consent Form

[Required for northern half of the province]

PROJECT TITLE:	Development Of the Father-Infant Relationship With an Infant Who Has Spina Bifida
INVESTIGATOR:	Linda Cook, Nursing Masters Degree Student Faculty of Nursing University of Alberta Edmonton, Alberta (XXX) XXX-XXXX
COSUPERVISORS:	Dr. L. Reutter PHD & Dr. A. Anderson PHD Faculty of Nursing University of Alberta Edmonton, Alberta (XXX) XXX-XXXX

PURPOSE: The purpose of this study is to describe and study the development of the father-infant relationship when the infant has spina bifida. The goal is to increase knowledge on which to base nursing care.

PROCEDURE: There are two interviews for this study. You may schedule them at convenient times for you. The first interview will probably last about 1 to 1 1/2 hours. The questions are about your experience of developing a relationship with your baby. You will be asked to talk about your baby and getting to know your baby. The second interview will be in person or by telephone. You may be asked questions about topics from the first interview and additional questions about relationship development with your baby. This interview is shorter, probably under 1 hour. The researcher will also call some fathers a third time near the end of the study to ask for their ideas about the findings. Each father can expect to spend no more than 3 hours participating in the study. The interviews can be done in your home, in an area agreed upon by the researcher and you, or by phone.

All interviews will be tape-recorded. A typed copy will be made of each recording. You will be asked to fill in a short form with general information about yourself and your family. The researcher will use these forms from all of the participants to describe the group of men in the study.

PARTICIPATION: There are no known risks for participants of this study, except for whatever possible discomfort you may feel talking about your baby's situation. You will not benefit directly from this study, except perhaps by having a chance to talk to someone about concerns about your baby. Results from this study, however, may help nurses to know more about fathers and how to help them better. This may help to improve the care that nurses give to families of children with spina bifida.

You do not have to be in this study if you do not wish to be. If you decide to be in the study, you may drop out whenever you wish by telling the researcher. You do not have to answer any questions whether asked or written. You do not have to discuss any subject if you do not want to. Taking part in this study or dropping out will not affect your child's care at the clinic. If you experience feelings that upset you while talking about your baby's situation, a counselling referral will be arranged, if you want help during the study.

Your name will not appear in this study. A code number will replace your name and any other identifying material on the typed interview copies and notes. The researcher will keep all interview records in one locked cabinet. She will keep consent forms and the code list in another locked file. Interview information may be used for additional study in the future, if the researcher receives approval from an ethics committee. The researcher will destroy consent forms and recordings after 7 years.

Quotes from the interviews may be used in reporting findings, but your identity and that of the hospital will not be revealed. You may call the researcher at the number above about any questions or concerns.

CONSENT: I acknowledge that the research procedures have been described and my questions answered. I know that I may contact the researcher about questions.

I realize that I do not have to participate in this study. I understand that I will receive no direct benefits from this study. I am aware that a counselling referral can be arranged if I feel upset during the study and want counselling. I have been told how records of this study will be kept confidential. I understand that I am free to withdraw whenever I may choose. I further understand that if I participate in the study or not, my child's care at the clinic will not be affected. I have been given a copy of this form to keep. I understand that if any information about abuse of someone under 18 years of age is disclosed by me during the study, the person conducting this study is under legal obligation to report it to the proper authority.

(Signature of Participant)	(Date)
(Signature of Researcher)	(Date)

REQUEST FOR SUMMARY:

If you wish to receive a summary of the study when it is finished, please complete the next section:

Name:____

Address:____

Consent Form

[Required for southern half of the province]

Research Project Title: Development of the father-infant relationship with an infant who has spina bifida.

Investigator: Linda Cook R.N., B.S.N, M.N. Candidate (University of Alberta).

Advisors: Dr. Linda Reutter, Faculty of Nursing, University of Alberta XXX-XXXX
Dr. Arnette Anderson, Faculty of Nursing, University of Alberta XXX-XXXX

Sponsors: Spina Bifida Association of Canada
Alberta Foundation for Nursing Research

This consent form, a copy of which has been given to you, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

Purpose: to describe and study the development of the father-infant relationship when the infant has spina bifida. The goal is to increase knowledge on which to base nursing care.

Procedure: There are two interviews for this study. You may schedule them at convenient times for you. The first interview will probably last about 1 to 1 1/2 hours. The questions are about your experience of developing a relationship with your baby. You will be asked to talk about your baby and getting to know your baby. The second interview will be in person or by telephone. You may be asked questions about topics from the first interview and additional questions about relationship development with your baby. This interview is shorter, probably under 1 hour. The researcher also will ask some fathers for their ideas about the findings near the end of the study. Each father can expect to spend no more than three hours participating in the study. The interviews can be done in your home, in an area agreed upon by the researcher and you, or by phone.

All interviews will be tape-recorded. A typed copy will be made of each tape. You will be asked to fill in a short form with general information about yourself and your family. The researcher will use all of these forms to describe the group of men in the study.

Participation: There are no known risks for participation in this study, other than whatever possible discomfort you may feel talking about your baby's situation. You will not benefit directly from this study, other than having a chance to talk to someone about concerns about your baby. Results from this study, however, may help nurses to know more about fathers and how to help them better. This may improve the care that nurses give to families of children with spina bifida.

You do not have to be in this study if you do not wish to be. You do not have to answer any questions whether asked or written. You do not have to discuss any subject you do not want to. Taking part in this study or dropping out will not affect your child's care at the clinic. If you experience feelings that upset you while talking about your baby's situation, a counselling referral can be arranged.

Your name will not appear in this study. A code number will replace your name and any other identifying words on the typed copies and notes. The researcher will keep all interview records in one locked file. She will keep consent forms and code lists in another locked file. Interview information may be used for additional study in the future, if the researcher receives approval from an ethics committee. Consent forms and code lists will be destroyed 2 years after all the children in the study reach the age of majority. The researcher will destroy all other study materials after 7 years. Quotes may be used to report findings, but identities of participants and hospitals will not be revealed.

If any information about abuse of someone under 18 years of age is disclosed during the study, the researcher is under legal obligation to report it to the proper authority.

Your signature on this form indicates that you have understood to your satisfaction the information regarding your participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the investigators, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time without jeopardizing your health care. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation. If you have further questions concerning matters related to this research, please contact: **Linda Cook (XXX-XXXX).**

If you have any questions concerning your rights as a possible participant in this research, please contact the Office of Medical Bioethics, Faculty of Medicine, The University of Calgary, at 220-7990.

______________________________ ______________
Participant Date

______________________________ ______________
Investigator Date

Witness Date

A copy of this consent form has been given to you to keep for your records and reference.

If you would like a summary of the study when it is finished, please complete the next section:

Name:____

Address:______________________________________